

ENLARGED AND REVISED EDITION

# FOUCAULT AND THE GOVERNMENT OF DISABILITY

**Shelley Tremain, Editor**

*Foucault and the Government of Disability*



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*Foucault and the Government of Disability*  
edited by Shelley Tremain

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Government of Disability*  
Enlarged and Revised Edition

*Shelley Tremain, editor*



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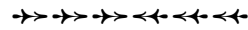


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SHELLEY TREMAIN



Foucault, Governmentality,  
and Critical Disability  
Theory Today

*A Genealogy of the Archive*

*An Editor's Prescience*



Ten years after the publication of the first edition of *Foucault and the Government of Disability* in early 2005, the far-reaching and transformative effects of the book for critical understandings of disability continue to unfold and multiply. Indeed, the first edition of the book has become a classic text in the library of critical disability theory and research, helping to shape a number of recent and ongoing discussions and debates within the interdisciplinary field of inquiry called “disability studies.” This introduction to the celebratory tenth-anniversary second edition of the book returns to the introduction of its forerunner in order to draw out the impact that the first edition has had on critical thought about disability, as well as to provide the overview of certain pertinent concepts, themes, and arguments in both Michel Foucault’s work and critical disability theory that the introduction to the former edition provided. For, like the first edition of *Foucault and the Government of Disability*, this second edition is intended for readers unacquainted with Foucault’s approach and with disability theory, as well as for avid readers of either or both.

Beginning in the Great Depression, and over the last forty years especially, people variously classified as “handicapped,” “disabled,” or “people with disabilities” have engaged in local and global organizing and campaigning, developing politicized conceptions of disability that counter medicalized approaches to it. These political conceptions of disability and the increasing consolidation and cultural presence of the social movements that spawned them have precipitated significant social change, including



the deinstitutionalization of thousands of people incarcerated in nursing homes and hospitals worldwide, retrofitting of government offices and public facilities to make them more physically accessible, redesign of urban infrastructures and landscapes, closed captioning on late-model televisions, and the growing recognition that disabled people constitute a marginalized and disenfranchised constituency. Disabled people's movements have also had an impact on academia, where the interdisciplinary (and counter-disciplinary) field of disability studies has emerged strongly. Courses in disability studies are now offered at universities and colleges throughout North America, Australia, New Zealand, and Europe, as well as in some regions of South America, Central America, Africa, the Middle East, and Asia. Academics who conduct their work under the rubric of disability studies or closely related fields such as philosophy of disability problematize the foundational assumptions of many traditional disciplines and fields of inquiry, as well as the methodologies they employ, the criteria of evaluation to which they appeal, and the epistemological and social positioning of the researchers and theorists invested in them. From within both autonomous programs and home disciplines, philosophers of disability, disability theorists, and disability researchers engage in a diversity of investigative and critical pursuits. They have, for example, identified the ways in which the institutional, structural, discursive, and material practices of the discipline of philosophy (and its sub-field feminist philosophy) have conspired to exclude disabled philosophers; pointed out the cultural and historical specificity of dominant Euro-American notions of corporeal attractiveness; analyzed how disability colluded with race in the formation of the modern nation-state; plotted histories of disabled people's resistance; traced genealogies of eugenic policies that culminate in contemporary reproductive technologies; critiqued representations of disabled people in the media and literature; and considered the intersections among race, disability, gender, class, and queer sexualities.

The desire to edit and publish a collection of essays on critical disability theory that revolve around the ideas of Foucault and, in particular, his ideas about governmentality, was borne out of my own intellectual concentration on and use of his work. The production and publication of a book on disability theory that would focus primarily on the work of a single author, especially an author whose writing seemed in many ways remote and abstracted from concrete analyses of disability, was, however, a novel venture, the prospects of which were uncertain. Although before publication of the first edition some disability theorists had used Foucault's ideas in interesting and creative ways, attempts to articulate a

Foucauldian stance on disability had, overall, been largely rudimentary. Nevertheless, the University of Michigan Press embraced the uncertainty involved in the publication of the book because Foucault's corpus had shown itself to be so generative of bodies of knowledge in other disciplines across the academy, including the disciplines of history, philosophy, the social sciences, medicine, architecture, and psychology. Within these and other academic and intellectual domains, Foucault's insights had by that time demonstrated their capacity to provoke scholars to question what was previously considered self-evident, timeless, unchanging, and necessary. Furthermore, his writings, lectures, and public statements had motivated scholars to critically reflect on the current situation, on the historical conditions that led to these formations, and on the way they might be differently perceived and transformed. To enable critical thinkers to develop new ways in which to conceive of their relationships with themselves and with each other, as well as their imbrication in relations of power, he provided the analytical tools of archaeology and genealogy, elaborating groundbreaking analyses of punishment, psychiatry, and sexuality to show how these tools could be employed. Given the rich theoretical offerings that scholars in a host of critical contexts had generated out of Foucault's work, LeAnn Fields, the editor of the *Corporealities: Discourses on Disability* series at the University of Michigan Press, thus believed that insofar as *Foucault and the Government of Disability* would expand and complicate the way that phenomena surrounding disability were at that time understood, the prospective book had the potential to enhance and enrich the field of disability studies and the gamble involved in the book's publication was, therefore, worth taking. This decision was prescient. Indeed, the first edition of *Foucault and the Government of Disability* has both enlarged and deepened Foucault's relevance and applicability to work on disability by responding to his call to interrogate what has been regarded as natural, inevitable, ethical, and liberating through analyses of a range of widely endorsed practices and ideas surrounding disability, including rehabilitation, community care, impairment, normality and abnormality, inclusion, prevention, genetic counseling, accommodation, and special education.

### *Critical Disability Theory With Foucault*



From 1971 until his death in 1984, Foucault held the Chair in the History of Systems of Thought at the Collège de France, where, during lectures

and seminars held weekly between January and June, he reported on original research that he was pursuing. In the introduction to the first volume of his three-volume edition of Foucault's writings, Paul Rabinow remarks that Foucault began his 1975–76 course “with a despondent, almost despairing apology for what he characterized as his thinking’s directionless drift” (Rabinow 1997, xv). As Rabinow explains it, Foucault had intended in these lectures to bring the work of recent years to completion that year but was at a loss about how to do so. In that first lecture Foucault lamented, “[T]hough these researches were very closely related to each other, they have failed to develop into any continuous or coherent whole. They are fragmentary researches, none of which in the last analysis can be said to have proved definitive, nor even to have led anywhere” (1980, 78; cf. Foucault 2003a). Rabinow suggests that this confession seems harsh, given that Foucault published *Discipline and Punish* in 1975 and volume 1 of *The History of Sexuality* in 1976. In fact, by the end of the course, Foucault had introduced a conception of power that he claimed had been overlooked in political philosophy. This form of power, crystallized in the final chapter of the first volume of *The History of Sexuality*, he called “biopower” or “biopolitics.” Before going further, I must pinpoint this form of power, this biopower, for it is vital to any Foucauldian analysis of disability.

From Aristotle to Locke and Rousseau, and on to Rawls, political philosophy has concerned itself with questions about legitimation and sovereignty. What are the foundations of legitimate rule? What is the nature of sovereignty? What is the most just form of government? On what grounds can rights be based? Although Foucault did not reject outright the significance of these questions for political thinking, he did refuse the idea of primal, or natural, rights that is presupposed by the juridical conceptions of political power from which these questions arise. In the terms of juridical conceptions, the individual possesses power (as one would possess a commodity) in the form of inherent, inalienable rights, the transfer or surrender of which (through a juridical act or a contract) constitutes a sovereign. In his lecture of January 7, 1976, Foucault argued to the contrary that power is not something that is exchanged, given, or taken back, but rather is *exercised* and exists only in action. In addition, Foucault disputed the assumption of many juridical conceptions that posits that power is fundamentally repressive. Though consensus and violence are the instruments or results of power, he remarked, they do not amount to its essential nature (2003a,

13). As he put it, “The exercise of power can produce as much acceptance as may be wished for: it can pile up the dead and shelter itself behind whatever threats it can imagine. In itself the exercise of power is not violence; nor is it a consent, which, implicitly, is renewable” (Foucault 1982, 220). For Foucault, the question that political philosophy should ask about power is this: *How*, that is, *by what means*, is it exercised? (217). Indeed, one of the most original features of Foucault’s analysis is the idea that power functions best when it is exercised through productive constraints, that is, when it *enables* subjects to act *in order* to constrain them (Tremain 2001, 2002). He argued, furthermore, that the continued preoccupation with juridical conceptions of power in modern political philosophy has obscured the productive capacity and subtle machinations of a form of power that began to coalesce at the end of the eighteenth century, namely, biopower.

This new technology of power—this biopower—that emerges in the second half of the eighteenth century takes as its object life itself, the life of the human qua living being, that is, the life of the human insofar as it is a living being. In his lecture of March 17, 1976, Foucault remarked that this new technology of power, this biopower, this biopolitics that begins to establish itself in the late eighteenth century, involves a set of measurements such as the ratio of births to deaths, the rate of reproduction, and the fertility of a population. These processes, together with a whole set of related economic and political problems, become biopower’s first objects of knowledge and the targets that it seeks to control. It was in this historical moment, Foucault noted, that the first demographers began to measure these phenomena in statistical terms. As these phenomena began to be taken into account, a new type of medicine developed, whose main function was public hygiene and whose institutions centralized the power of the new medicine, normalized its knowledge, and coordinated the care that is distributed under its auspices. There were campaigns to educate the public and medicalize the population. In order to deal with accidents, illnesses, and various anomalies, biopower established charitable institutions and economically rational mechanisms such as insurance, individual and collective savings, and safety measures. Since the phenomena with which this biopolitics (this biopower) was concerned became pertinent only on a mass level, constants that pertained to the collective had to be established. In this regard, biopolitics involves the introduction of mechanisms whose functions include forecasts, statistical estimates, and overall measures, and whose purpose is to intervene at the level of generality

of these phenomena. Regulatory mechanisms are put into place that prescribe norms, adjust to an equilibrium, maintain an average, and compensate for variations within the “general population,” a group of living human beings whose constitution *as* a “population” is in large part due to this form of power, and especially to the surveillance of “sex” that it requires. In addition, security mechanisms partition the random element of populations from the collective at large in order to maximize the conditions conducive to life (Foucault 2003b, 238–63). In volume 1 of *The History of Sexuality* (1978), Foucault explained the rationale behind biopower’s normalizing strategies:

[A] power whose task is to take charge of life needs continuous regulatory and corrective mechanisms. . . . Such a power has to qualify, measure, appraise, and hierarchize, rather than display itself in its murderous splendor; it does not have to draw the line that separates the enemies of the sovereign from his obedient subjects; . . . it effects distributions around the norm. . . . [T]he law operates more and more as a norm, and . . . the juridical institution is increasingly incorporated into a continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulatory. A normalizing society is the historical outcome of a technology of power centered on life. (144)

As the first edition of *Foucault and the Government of Disability* demonstrated, the importance of critical work on biopower (biopolitics) to analyses of disability should not be underestimated. For during the past two centuries, in particular, a vast apparatus, erected to secure the well-being of the general population, has caused the contemporary disabled subject to emerge into discourse and social existence. Among the items that have comprised this expansive apparatus are asylums, income support programs, quality of life assessments, workers’ compensation benefits, special education programs, regimes of rehabilitation, parallel transit systems, prostheses, home care services, telethons, sheltered workshops, poster child campaigns, and prenatal diagnosis. These (and a host of other) practices, procedures, and policies have created, classified, codified, managed, and controlled social anomalies through which some people have been divided from others and *objectivized* as (for instance) physically impaired, insane, handicapped, mentally ill, retarded, or deaf. Foucault argued that, in recent times, practices of division, classification, and ordering around a norm have become the primary means by which

people are individualized, come to be understood scientifically, and even come to understand themselves in this mode.

An understanding of biopower's capacity to objectivize people in this way illuminates Foucault's remarks about the dual meanings of the term *subject* as they pertain to the circumstances surrounding disabled subjects. For Foucault, to be a subject is, in one sense, to be subject to someone else by means of control and dependence and, in another sense, to be tied to one's own identity by a conscience or self-knowledge. Both senses of the term imply a form of power that subjugates and makes subject to (Foucault 1982). Because he refused to conceive relations of power in strictly juridical terms, Foucault maintained that analyses of power should not aim to identify some overarching or distant font of subjecting power, but rather "should try to grasp subjection in its material instance as a constitution of subjects." Hence, work on biopower and the dual nature of the subject can help us to "discover how it is" that disabled subjects "are gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, desires, thoughts, [and so on]" (Foucault 1980, 97). In 1982, Foucault remarked that the goal of his work over the previous twenty years had not been to analyze power, but rather to write a history of the different modes through which human beings are transformed into subjects (Foucault 1982). In another, earlier context, Foucault had remarked that in his work he had been trying to render evident the "constant articulation of power on knowledge and of knowledge on power," especially with respect to the subject. Power—that is, its exercise—he argued, perpetually creates knowledge and knowledge constantly induces effects of power (Foucault 1975).

Foucault was particularly interested in the knowledges with respect to the subject that comprise the disciplines that have come to be called "the human sciences," disciplines such as criminology, sociology, psychiatry, and psychology. He was concerned to show how closely the emergence of these knowledges over the last two centuries has been enmeshed in the problems and practices of (bio)power and the social management of individuals (Gordon 2000). In addition, he suggested that analyses of power should take as their starting point a new kind of counter-politics (what he called "strategic reversibility"), which these knowledges have inadvertently spawned. For individuals and *juridically constituted* groups of individuals have responded to subjecting practices directed in increasingly intimate and immediate ways to "life" by formulating needs and imperatives of

that same “life” as the basis for political counter-demands, that is, by turning them back as focuses of resistance (Gordon 1991). That Foucault’s political activities and scholarship were in large part directed at issues raised by prisoners’ rights groups, ex-inmates of psychiatric institutions, refugees, and gay men’s alliances is well known.

In addition to the notion of biopower, other elements of Foucault’s ideas are indispensable for a Foucauldian analysis of disability, and none more so than the notion of the subject. These elements, biopower and the subject, are inextricable from Foucault’s notions of government and liberalism.

In Foucault’s lectures of 1978–79, he linked his claims about biopower to his approach to the theme of government. Power, he argued, is more a question of *government*, that is, the direction of conduct, than it is a question of confrontation between adversaries. The term *government*, he remarked in 1982, should be understood in its sixteenth-century sense to refer to any form of activity that aims to shape, guide, or affect the conduct of some person or persons; furthermore, he proposed that the term be defined, in general, to mean “the conduct of conduct.” As an *activity*, government can concern one’s relation to oneself, interpersonal relations that involve some form of control or guidance, and relations within social institutions and communities, as well as relations concerned with the exercise of political sovereignty (Gordon 1991). Indeed, Foucault adopted this earlier, broad meaning of *government* because it encompasses not only legitimately constituted forms of political and economic subjection, but any mode of action, more or less considered and calculated, that is bound to structure the field of possible action of oneself or others (Foucault 1982). In other words, when relations of power are construed as government, that is, the direction of conduct, governmental practices should be understood to include state-generated prohibitions and punishments and global networks of social, economic, and political stratification (the deleterious effects of which congeal disproportionately along disabling, racialized, and gendered lines), as well as normalizing technologies that facilitate the systematic objectivization of subjects as deaf, criminal, mad, and so on, and techniques of self-improvement and self-transformation such as weight-loss programs and fitness regimes, assertiveness training, Botox injections, breast implants, psychotherapy, and rehabilitation. Despite the fact that power appears to be merely repressive, the most effective exercise of power, according to Foucault, consists of guiding the possibilities of conduct and putting in order the possible outcomes. In his most succinct articulation of power as government, Foucault wrote:

[W]hat defines a relationship of power is that it is a mode of action which does not act directly and immediately on others. Instead it acts upon their actions: an action upon an action, on existing actions or on those which may arise in the present or the future. . . . The exercise of power . . . is a total structure of actions brought to bear upon possible actions; it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action. (1982, 220)

The first edition of *Foucault and the Government of Disability* brought to the center of discussion in critical disability theory the conception of power as government (“the conduct of conduct”), a conception of power that contrasts starkly with the “juridico-discursive” (to use Foucault’s term) conception of power that, to that point, much disability theory and activism had taken for granted. In so doing, the first edition showed that a different conception of force relations was available to critical disability theorists. This conception of power as productive, as circulating, and as coming from below motivated many disability scholars to reconsider and indeed more critically examine aspects of social, economic, cultural, subjective, and intersubjective existence that they had previously regarded as falling outside the reach of disabling power. Recall that in the terms of juridical conceptions power is construed as a fundamentally repressive thing that is possessed by a centralized external authority, such as a particular social group, a class, an institution, or the state, and reigns over, and down upon, others. The “social model of disability,” which, until the publication of the first edition, had been predominant in the disabled people’s movement in the United Kingdom since the late 1970s, and which at the time had received increasing attention internationally, is a paradigmatic example of the juridical conception of power that once prevailed in disability studies. With the publication of the first incarnation of *Foucault and the Government of Disability* and the wide circulation of the idea of power as government, however, critical disability theorists were given tools with which to think beyond and outside of the social model. When governmentality entered the lexicon of disability studies, that is, when the ideas of force relations as productive and the direction of conduct were introduced into the conceptual apparatus of disability scholarship, critical disability theorists began to recognize that a significant alternative to the construal of power assumed on the terms of the social model was possible and, in particular, an alternative



to the social model's construal of the relationship between impairment and disability was conceivable (see Tremain 2005; see also Tremain 2001, 2002, 2006, 2010). That the conception of power as government has inspired the publication of a growing number of essays in *Disability Studies Quarterly*, *Disability & Society*, and other academic journals, as well as in various collections and anthologies is testament to the formative impact that this analytical shift continues to have on critical thinking about disability.

Foucault was concerned with philosophical questions that surround rationalities of government, that is, systems of thinking about the nature of the practice of government. A rationality of government, as Foucault explained it, is a system of thinking about the practice of government that has the capacity to *rationalize* some form of that activity to those who practice it and those upon whom it is practiced, where this capacity entails rendering thinkable *and* rendering applicable or acceptable. Foucault coined the term *governmentalities* to refer to these governmental rationalities, and he used this term almost interchangeably with the phrase *arts of government*. In his important 1979 lecture entitled "The Birth of Biopolitics" (1997), Foucault remarked that the phenomena that from the eighteenth century onward began to appear as problems that require management cannot be dissociated from the framework of liberal governmentality within which they emerged *as* problems and developed their urgency.

Foucault believed that this emergence of liberal governmentality evinced a transformation from the political and economic thinking that had conditioned earlier cameralist and mercantilist rationalities and a new configuration of the relationship between knowledge and government. Although these earlier rationalities of government had sought to rationalize a growing governmentality and its regulation through the existence and strength of the state itself, liberalism, Foucault asserted, ushered in the principle "One always governs too much," or one must always suspect that one governs too much (Foucault 1997; Gordon 1991). To be sure, any rationalization of state government aims to maximize its effects and diminish (to the greatest extent possible) its political and economic cost. Foucault (1997) argued that liberal rationalization is innovative, however, insofar as it starts from the assumption that government cannot be its own end. Foucault's perspective with respect to liberalism in this regard is distinctive, for he was concerned to understand liberalism not simply as a doctrine, or set of doctrines of political and economic theory, but rather as a style of thinking that is quintessentially concerned with the art of governing (Gordon 1991).

Foucault was not a libertarian; nevertheless, he was intrigued by liberalism, especially because of what he regarded as its “polymorphism,” that is, its capacity to continually refashion itself in a practice of auto-critique. In fact, Foucault viewed liberalism as a form of critical reflection on governmental practice itself. Liberalism, he asserted, can be found simultaneously, but in different forms, as both the regulative scheme of governmental practice and the theme of a (sometimes) “radical” opposition. As he explained it, liberalism constitutes a tool for the criticism of reality, that is, for the criticism of (1) a previous governmentality that one tries to shed, (2) a current governmentality that one attempts to reform and rationalize, and (3) a governmentality that one opposes and whose abuses one tries to limit (1997, 75). In addition, he suggested that insofar as the counter-discourses that biopower inadvertently generates initially emerged within liberal governmentality, the counter-demands that are advanced under the auspices of these discourses are also historical effects of liberalism’s polymorphic character. Indeed, insofar as the arguments and claims to entitlement that disability theorists and the disabled people’s movement advance are responses to the subjecting governmental practices of biopower, a Foucauldian stance on the current state of disability politics assumes that these political calls themselves are salient effects of liberalism.

### *The Shape of Things to Come*



The second edition of *Foucault and the Government of Disability* includes all the chapters in the first edition of the collection and retains the same four parts as the first edition, with each part reflecting a broad area of thought on which Foucault’s work concentrated. As a celebratory tenth-anniversary publication, nevertheless, this second edition of the collection also includes four additional chapters in a new part of the book entitled “Disability and Governmentality in the Present.” Furthermore, an updated and expanded index is appended to these five parts of the book. In the introduction to the first edition of the collection, I had indicated that, although the sixteen (original) chapters included in the collection are relatively autonomous, they were written, edited, and arranged in a fashion that limits the repetition within the collection of certain concepts, claims, and arguments that should be instructive for an analysis of disability that follows from Foucault’s approach. The same organizational strategy applies to the twenty chapters contained within this sec-

ond edition of the book, that is, some of the later chapters in the book presuppose an understanding of certain arguments and concepts that are explained or considered in earlier chapters. Indeed, the four new chapters in the fifth part of this second edition build upon and elaborate many of the ideas, arguments, and themes that the first edition introduced or suggested. Thus, readers of this book unfamiliar with Foucault's work, disability theory, or both might find that they will derive the most benefit from the book if they read its chapters according to the sequence in which they have been arranged.

As the introduction to the forerunner of this second edition noted, the chapters in "Epistemologies and Ontologies," the first part of the book, variously take up Foucault's concerns with the mutually constitutive and reinforcing relation between power and knowledge; the ontological status of the objects studied in the human sciences; the emergence of certain human phenomena as problems for power/knowledge; and the constitution of subjects by and through medical, juridical, and administrative practices. Foucault argued that a "history of the present" would enable an understanding of the human subject's current circumstance, that is, would facilitate a historical awareness of its current situation. The chapters in the second part of the book, "Histories," utilize this insight by drawing attention to the importance of historical analyses for critical disability theory. The contributors to "Governmentalities," the third part of the book, use Foucault's analytical tools in order to interrogate various concrete manifestations of disabling government. Recall that, for Foucault, government can concern any activity that affects one's own conduct or the conduct of others. A rationality of government (a "governmentality") renders some form of that practice of government ("conduct of conduct") conceivable and applicable to subjects who govern and to subjects who are governed, as well as to how subjects govern themselves, that is, their own conduct. In fact, Foucault maintained that the notion that the subject's practical political choices can be determined within the space of a theoretical text trivializes the act of moral decision making to the level of mere aesthetic preference (Gordon 1991, 6). The contributions to the fourth part of the collection, "Ethics and Politics," thus variously put into relief the inextricable relation between ethics and politics.

As I have intimated, the four chapters in the new fifth part of the book demonstrate the impact that the first edition of *Foucault and the Government of Disability* has had on the terrain of critical thought about disability. In

particular, the four new chapters offer sophisticated understandings of disability and its implication in, and mutual constitution with, axes of power such as race, gender, nationality, and sexuality, as well as provide fresh interpretations of Foucault that the first edition of the collection directly or indirectly inspired and motivated. Danielle Peers's textually rich contribution documents the genealogy of her subjectivation as a Paralympic athlete and how this subjection as a competitive wheelchair athlete disciplined her body, mind, and breath, rendering her simultaneously docile and empowered. In Anne McGuire's highly original new chapter in the collection, she draws upon Foucault's claims about governmentality and biopower in order to argue (among other things) that current authoritative discourses with respect to "the war on terror" are imbricated in and condition contemporary advocacy discourses on "the war against autism." Ashley Taylor considers the critiques of philosopher John Rawls's theory of justice that a number of philosophers of disability have recently articulated. In a measured and sympathetic treatment of these critiques, Taylor draws upon both Foucault's claims about the productive character of power and Judith Butler's work on "normative violence" in order to show why these critiques are, nevertheless, unsatisfactory. The second edition of *Foucault and the Government of Disability* closes with Kateřina Kolářová's provocative new chapter about assisted suicide. Kolářová shows how Foucault's insights about liberal governmentality can enable us to understand how current discourses on "good death" and "choice" with respect to assisted suicide for aging and disabled people are tied to notions of empire and capitalism in the West.

With four new and pathbreaking chapters, the tenth-anniversary second edition of *Foucault and the Government of Disability* poses the same series of challenges that its predecessor did and introduces new points of contention and controversy. In particular, the collection challenges readers of Foucault to reconsider the ways in which they understand his insights and claims; dares specialists on Foucault to expand the uses to which they have put his work, particularly with respect to considerations of disability; encourages theorists and researchers of disability to continue to think beyond accepted dogmas and outside of dominant frameworks of analysis; and urges disability activists to reaffirm that insurrection takes place, and must take place, through a diversity of modes, in varying intensities, and across a spectrum of social, political, cultural, economic, educational, and personal contexts.

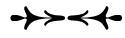
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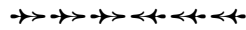


*Epistemologies and Ontologies*





MARTIN SULLIVAN



## Subjected Bodies

### *Paraplegia, Rehabilitation, and the Politics of Movement*

Following paralysis, there is a radical break in how paraplegics experience their bodies, in what they are physically able to do, and in the ways in which their bodies are interpreted socially, assigned meanings, and allocated space in which to do and be. Foucault's notions of biopower, normalization, and the carceral network can help us to unravel the ways that paraplegics are constituted as subjects following their accidents; in addition, the approach enables us to consider how, in various ways, they resist this subjectification. By drawing upon Foucault's analysis of disciplinary institutions (in particular, the institution of medicine), I show how the medical power that circulates in a specific facility for the rehabilitation of spinal-cord-injured people is, in the first instance, directed at producing a *certain type* of body—a governable and, hence, productive body—and a *certain type* of subject—namely, the paraplegic body-subject. I outline how this technique is enacted by drawing upon the experiences of ninety paraplegics who were rehabilitated (processed?) at the Otago Spinal Unit (OSU)<sup>1</sup> in Aotearoa New Zealand, during its first ten years of operation (1976–86). In particular, I focus on the admission of recently-injured paraplegics to this rehabilitation hospital, the totalizing aspects of treating motor impairment, and regimes of bodily maintenance in order to examine ways in which struggles between medical power and subjective resistance were engaged on the battlefield of paraplegic bodies in the context of a specific theater of war: the OSU.

#### *Foucault's Legacy*



Foucault's later work addresses the question of how social institutions act on the body and the implications that these actions have on the way in

which a person is constituted as a subject. Foucault approaches these questions through an “analysis [of] power relations” (Foucault 1982, 219), which focuses on the deployment within the modern states of disciplinary techniques, normalizing judgment, biopower, and the carceral network. His objective is to create a history of the modes by which human beings are objectified and transformed into subjects (208). Central to this history is an analysis of the operation and relations of power in terms of various techniques and technologies of discipline, surveillance, and punishment. These techniques emerged at the end of the eighteenth century and the beginning of the nineteenth century, a period during which the target of punishment shifted from the corporeal to the psychological. In that historical moment, bodies (which formerly had been subjected to the spectacle of torture and death) became the objects of incarceration, surveillance, and discipline. The goal of punishment became reform of the prisoner, who might one day emerge from the reflective solitude of the prison cell as a new subject (Foucault 1977, 11). It was believed that, locked in a cell, the criminal could not evade the ever-present gaze of the warder, a gaze that would gradually be interiorized “to the point that [the prisoner becomes] his own overseer . . . exercising . . . surveillance over, and against, himself” (Foucault 1980a, 155).

Prisons were only one (though, arguably, the first) node in a network of disciplinary and regulatory practices that emerged in the modern period. This larger grid, which Foucault calls “biopower” (1979, 140), consists of various institutions—educational, industrial, military, medical and psychiatric, the police, assorted apparatuses of the state—and constitutes a “carceral archipelago” (Foucault 1977, 297), which transports the disciplinary practices of the penal institutions into the wider social body. The carceral operates as a unity by adhering to a common standard of “normalizing judgement,” which penetrates all levels of society, examines, judges, roots out the abnormal, and prescribes appropriate means with which to rehabilitate individuals who deviate from the norms that it has already put in place in order to subsequently restore the individuals to these norms. Thus, a fine net of disciplinary power must be cast over an increasing number of areas of life, which imposes

a whole micro-penalty of time (lateness, absences, interruptions of tasks), of activity (inattention, negligence, lack of zeal), of behavior (impoliteness, disobedience), of speech (idle chatter, insolence), of the body (“incorrect” attitudes, irregular gestures, lack of cleanliness), of sexuality (impurity, indecency). (1977, 178)

Every aspect of everyday life is made subject to a whole series of procedures designed to enforce normality: indeed, “[T]he slightest departures from correct behavior [are made] subject to punishment. . . . [E]ach subject finds himself caught in a punishable, punishing universality” (178).

In short, biopower is directed solely at “the body”—its capacities, its requirements, and its potentialities. It coalesces around the social body in the form of the administration of populations; in addition, it coalesces around the individual body in a variety of settings (such as hospitals, prisons, and schools), where it takes particular forms. The objective is to render bodies “docile,” that is, as ones that may be “subjected, used, transformed and improved” (1977, 136). This “making bodies docile” is achieved through disciplinary practices that divide the body into units and, in turn, subject those units to precise and calculated training. Hierarchical observation (surveillance), normalizing judgment, and the examination (in hospitals, prisons, and schools) are the techniques of “correct training” (1977, 170–92). The end-product of these regimes is a disciplined subject who is both efficient and productive. The subject is *productive* because one effect of surveillance is to make the body an object of knowledge that yields a particular “truth”; the subject is also *efficient* because the “truth” that is inscribed upon a specific body increases its utility, makes it calculable, comprehensible, and compliant.

The carceral’s various institutions, organizations, and associations are the sites in which bodies are compared, differentiated, hierarchized, diagnosed; in which judgments of normality and abnormality are made; and in which appropriate methods of correction and rehabilitation are ascertained in order to restore deviant bodies to the norm. By making it possible to measure gaps between individuals and to render transparent the distinctions that these differences are claimed to signify, normalizing judgments simultaneously impose homogeneity on the social group and individuate certain subjects. In other words, the disciplinary power flowing through the carceral is productive, rather than repressive. Disciplinary power not only “fabricates” the individual; in addition, “[I]t produces reality; it produces domains of objects and rituals of truth. The individual and the knowledges that may be gained of him belong to this production” (1977, 194). These new procedures of individualization, and the production of knowledge about human subjects that is concomitant with them, firmly locate the carceral network as the condition that made the human sciences (psychiatry, penology, psychology, and so on) historically possible (1977, 305).

*Medicalizing Bodies, Medicalized Subjects*

In contemporary society, the hospital is an important node in the carceral where “dividing practices” (Foucault 1982, 208) objectivize the subject as either sick or healthy, curable or incurable, complete or incomplete, normal or abnormal. The medical judges (the priests and priestesses of secular society), having assumed the right to absolve or condemn, exercise immense power over people’s bodies, their health, and their lives. When a person is paralyzed, that individual’s body becomes the object of this medical power. Removed to the hospital, or spinal unit, the various parts of the paralyzed body are subjected to intense diagnosis, classification, documentation, monitoring, and discipline in order to render them knowable and productive, to increase the body’s utility.

Diagnosing and examining the paralyzed body is not a bad thing per se. If the paralyzed body were not invested with specific techniques and knowledge, it would quickly deteriorate and die. If, however, Foucault is correct about dividing practices, then it would be reasonable to expect that, during the process of rehabilitation, the body of the spinal-cord-injured individual would be objectivized *as paralyzed*, the individual would be subjectivized *as paraplegic*, and the subject would come to know itself in these terms. Others would also come to “know” the spinal-cord-injured individual in these terms. During this “ritual of truth,” the paralyzed body is inserted into—that is, becomes part of—the medical (and rehabilitative) discourse on paraplegia that maintains the person as a particular subject, one who knows and experiences its body in a highly medicalized way, and for whom the possible ways to be a subject are constrained by the disciplinary techniques that knowledge imposes. In short, rehabilitative medicine fits Foucault’s description of subjecting power insofar as rehabilitation is “a form of power . . . which categorizes the individual . . . attaches him to his own identity, imposes a law of truth on him which he must recognize and which others must recognize in him. It is a form of power which makes individuals subjects” (1982, 212).

As the last-cited remarks demonstrate, Foucault does not treat power as something that is “acquired, seized, or shared,” which operates in a binary fashion from the top down onto increasingly limited groups. Rather, power is everywhere “exercised from innumerable points,” is multidirectional, comes from below, sideways, from above, and is a general matrix of non-egalitarian and mobile force relations. As Foucault points out, furthermore, “[W]here there is power, there is resistance, resistance which is often mobile

and [transitory, producing cleavages, fracturing unities], furrowing across individuals themselves, cutting them up and remolding them” (1979, 96).

From the remarks above, we can derive a sense of the subject as one who is “divided inside himself” (1982, 208), resisting the imposition of a totalizing identity. For Foucault, this form of resistance involves the notion of “strategy” (224), or the choice of “winning solutions,” which offer the possibility of contestation and “points of insubordination which . . . are a means of escape” (225).

Drawing upon these insights, Haber argues that “the very self is thus fragmented into antagonistic sites of power” (1994, 105). In slipping from one site to another, the subject is able to effect an escape from any totalizing subject position. In short, a Foucauldian approach assumes that no individual subject has a single, complete, or unitary self-identity. To the contrary, the subject can occupy any of a number of subject positions,<sup>2</sup> and can resist normalization from “mobile and transitory” identity standpoints, even if those various standpoints are themselves normalized subject positions. Hence, one would expect the paralyzed individual to resist the normalizing regime of medical power in the spinal unit that operates to impose a totalized identity of *paraplegic*. Indeed, the paraplegic individual has as its points of insubordination the various subject positions that it occupied as a nondisabled person in its former, nonparalyzed body.

### *Admission: Subjugation to Medical Power*



Admission to the Otara Spinal Unit marks the institutional phase of a person’s rehabilitation. Most residents of the unit are admitted to it while they are still in a dependent and bewildered, post-injury state of mind, knowing only that they cannot feel or move their legs. Medical power is diligently asserted over the new admissions, especially the ones who are still in the acute phase. These recently admitted patients learn very quickly that they have not only lost the power to move and feel their bodies; they have, in addition, lost possession of their bodies, in terms of knowledge and control. By contrast, medical professionals, insofar as they have read the right textbooks, know how the patient should feel, and know what needs the patient has; moreover, medical personnel are in a position to enforce their knowledge. In a short space of time, the paraplegic individual becomes aware that s/he is now in a situation where medical knowledge and medical power prevails. As one participant in my research told me:

[T]he first day that I got moved to the spinal unit . . . they laid me on pillows and there was a pillow to spare, as I'm that much shorter than most. . . . So they lifted me up and laid me again. And it ended up so they had a bit of me on each of the pillows but it meant that I didn't have a pillow under my fracture side. So it was really, really painful. I said, "I don't think you've laid me right." And they said, "Well, how would you know? You've just arrived here." And I said, "Well, I can see by the diagram that you're working from that I'm not in the right position," and they said, "Well, that's it. We've moved the team now and we have to do a full team lift, so you're stuck like that." And it was really, really painful, so I said, "Oh, well, what's your position on pain relief here?" And she said, "Are you in pain?" And I said "yes." And she said, "That's good, because it means you've got feeling, doesn't it?" and walked off. And I just had to lie there in agony until the afternoon shift came on.

Another participant in my research, who had been the driver of a car in which someone had been killed and against whom criminal charges were, therefore, pending, experienced similar treatment on admission to the OSU. This individual, who had sustained a neck injury in the crash a fortnight earlier, was, nevertheless, still experiencing considerable pain. Numerous x-rays had failed to detect a cause for the pain. Given the circumstances surrounding the individual's injury, the pain was attributed to imagination: an obvious grab for mitigating sympathy. The fact that the details of the fatal incident preceded the individual's arrival at the spinal unit further aggravated the situation. As the individual explains it, "The day I arrived there, I had a neck roll in—I had a sore neck—and they just whipped it out: 'No, you shouldn't have that. There's no need for that.'" The rough justice continued:

When I sat up, I couldn't even hold my head up properly. And when they were doing full-turn lifts, I used to plead with them to hold my head for me and they said, "No. You should be able to hold it for yourself." But I could never do any of that. They didn't even want to admit that there was any injury there. . . . Numerous times [I complained]. They said: "Oh, you've been through a lot."

The professionals ignored this individual's own corporeal account, despite observing decreased sensation and strength in the individual's right arm. Moral judgments seem to have precluded immediate and objective exploration of the symptoms. Ten weeks after the injury, evidence of dam-

age to the cervical area of the spine at C<sub>3</sub><sup>3</sup> was finally obtained and appropriate treatment followed.

Two additional instances of the deployment of medical power in the unit illustrate its subjugating and alienating effect. In the first episode, a woman is denied dialogue on her diagnosis, treatment, and rehabilitation program.

I queried an orthopedic surgeon and he went right off his face, . . . and all that I was doing was asking a question and he said, “Don’t you give in” and “How dare you judge or criticize my judgment or query my judgment?” And I thought, “Who do you think you are? God or something?”

Indeed, medical power was pervasive: patients had little, if any, meaningful input into their rehabilitation regimes. They were inserted into pre-existing programs, whose pre-existing schedules and routines did not allow for personal differences between them. In addition to the frustration that most of the people who had been admitted to the unit felt due to this “doctor knows best” attitude, many of them expressed anger about the lack of in-depth information that was provided to them about (for instance) the immediate and long-term effects of paraplegia, current treatments, and individual progress in rehab programs. In general, these paralyzed people believed that the medical experts either did not know the answers or (for some reason that these people could not fathom) were withholding information from them with regard to their own paralyzed bodies and future lives. Furthermore, often information that could be extracted from one member of the medical team contradicted the information that was received from another. In effect, patients on the unit were kept in a twilight world, one in which no clear answers to their questions were given. As one research participant put it,

I was kept in the dark too much. I wanted to know what the future held in store. I feel the patients’ rights . . . were crushed. . . . I resented most of the attitudes that were shown by the trained staff. It felt as though I was in a prison, rather than being nursed back to health.

One could argue that in this environment medical power was undermined, that it lost its legitimacy. Alternatively, one might expect that in this environment the paralyzed body would become increasingly mysterious and alienating, that life and self would become ever more tenuous and con-



tingent. Disoriented, the body-subject would become even more susceptible to the medical power that plays across its body, imposes routine and regularity on it, and creates it as a productive, paraplegic body.

*Treating Motor Impairment: Totalizing Aspects*



Many participants in my research emphasized the fact that a totalizing approach is adopted at the Otago Spinal Unit. That is, many of them believed that they had been viewed entirely in terms of their paralyzed bodies, that programs were overwhelmingly directed at building up the normal, innervated, nonparalyzed parts of their bodies in order to compensate for those parts that were now paralyzed. This, almost total, emphasis on the body, the physical, was carried out at the expense of the emotional and psychological. As one individual who had been a patient on the unit remarked,

They do not sit down and talk to you and see what you're thinking. . . . I used to fight with [the physiotherapist] and they used to say, "You should enjoy going to physio. You should want to get on." But I said I needed time to myself, but they would not give that time for mental health, psych yourself up for whatever is ahead of you. . . . You're not a person, you're a number.

Another participant in the research articulated similar concerns: "I didn't mind the routine, it was the attitude. They weren't patient enough with every individual person's body."

For many participants, the most infuriating aspect of this totalizing approach was the appeal to remote paraplegic bodies in medical textbooks and the use of these textual archetypes as a yardstick against which their real bodies, what they were capable of doing, and their individual characters, were measured. In short, the medical personnel rigidly adhered to standard procedures and goals that allowed little deviation from a textbook ideal of the "patient with paraplegia." Not surprisingly, some paras felt as if they had been sold short in terms of the recovery that they might have achieved, or had been labeled as "no-hopers" who had not reached their full potential as prescribed in the textbooks.

Instead of treating you like an adult, an individual person, you are just Number 6, Room 10. OK, it is his time to shit, it is his time to piss, put him in his chair, feed him, and get him the hell out of here. . . . [But]

everyone is different, every person is different, every accident is different. No two accidents are the same; but if you are a L3 para, then, OK: there is your break, and all other L3 paras can do this, and that's it. If you can't do that, then, what the hell is wrong with you?

The imposition of a universal bowel and bladder program was one of the most deeply personal ways that many of the participants in my research felt that the impetus of the unit was to turn them into totalized, paraplegic bodies: everyone was expected to move their bowels first thing, every second morning, regardless of their preparalysis routine. The standardization of bowel evacuations may well have contributed to the convenient management of the spinal unit; however, it also sent a subliminal message to individuals on the unit that they were now part of a homogenized paraplegic population.

A message of the same order was discerned from the general lack of respect for patients' privacy. The disregard for patient privacy was most evident in the insensitivity and lack of care shown to female patients in the course of their bladder-training programs. As one female participant stated, "It's another body. And because they are so used to it, they expect you to be used to it too."

Under these conditions, it is not surprising that many participants felt that they had been treated like numbers, had been normalized as "cripples" and as "paraplegics," rather than as individual subjects. Obviously, any rehabilitation of the motor-impaired, paraplegic body will involve concentrated physiotherapy that aims to build up the upper body; however, the almost total emphasis on the restoration of physical mobility riled the majority of participants with whom I spoke. Many of them believed that the aim of this virtual fixation with restoration was to turn them into subjects of *a certain kind*, a fear that was clearly expressed by a young male:

All they do is give you physiotherapy, teach you how to dress yourself and do transfers. It's like they are trying to turn you into a cripple.

### *Producing Docile Bodies: Techniques of Bodily Maintenance*

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The first stage of the process of producing a specific subject from a particular body lies in rendering that body docile in order that it may be "used, transformed and improved" (Foucault 1977, 136). Medical power achieves

this feat in the spinal unit by dividing the paraplegic body into parts, and in turn, subjecting each of these parts to precise and calculated training. Rendering the paraplegic body docile is, thus, achieved via the inculcation of techniques of bodily maintenance, foremost of which are the techniques devised to deal with incontinence and to maintain the integrity of the skin.

### *Incontinence*

Until a regime of regularity is imposed upon the evacuation of bodily wastes, the paraplegic body can hardly be considered docile. Thus, it is here, in the establishment of a regime of regularity, that the greatest struggle between medical power, the body, and the paraplegic subject takes place.

Anatomy combined with technology means that males are confronted with far fewer problems than females in the area of bladder management. Some of the men in my research did, nonetheless, feel violated by the surgical procedure that had been performed on them to relieve ostensible problems with urine retention (which can have serious health consequences). These men, who were young at the time when the surgery was performed on them, now complain bitterly that they were not sufficiently counseled about the full implications of the procedure, which induces a continual, free flow of urine from the bladder. As one man remarked:

I've had one of those; I was told I needed one. I wasn't really told what it was, what it would mean. The arrogance. Doctors, man. Arrogant bastards. . . . They gave me one. And they didn't have to.

The problems that male paras encounter in relation to bladder management pale in significance when placed alongside the problems with bladder management that female paraplegics experience. For women paras, attempts are made to train the bladder to empty itself at regular intervals; however, accidents do happen. Because of these incidents, this training period can be a truly degrading and depressing time for these women. One would, therefore, expect a spinal unit to be a generally safe and supportive environment in which women could learn techniques of bladder management. My research indicated, however, that this is not always the case. For example, one woman with whom I spoke believes that her entire rehabilitation was delayed by the inflexible approaches that the unit staff adopted toward her bladder management.

To me, it's [bladder training] the most humiliating and worst thing. . . . I'm annoyed they let me put up with it for so long. Being wet all the time. It did nothing for my confidence. I kept saying, "Give me an indwelling [catheter]" and they wouldn't let me have it. I'd want to go out for the day and I'd ask for an indwelling and they'd say "No," so I didn't go. . . . That was the reason I was in there so long, . . . because I could never do any physio, 'cause I'd go over there and I'd be wet.

Another woman spoke of the confused and confusing advice that she was given, the lack of privacy, the depersonalized manner in which nurses delivered it, and the messages that this imparted to her about her body: "One nurse will come in and another will come in to talk to her. And you're thinking, 'Shit, [I'm] just another body.'"

Most of the paras (female and male) with whom I spoke nominated incontinence as the worst aspect of paraplegia. Incontinence, coupled with a loss of skin sensation, clearly establishes a mind/body dualism unfathomable to the uninitiated. Incontinence reveals one's body, in all of its excessiveness and unruliness, as anything but productive and docile. The management techniques that must be employed in order to restore this docility and productivity to the paraplegic body, demand that the paraplegic subject adopt a mechanical, disconnected, and *disembodied* relationship with its body. Once this relationship is established, the body becomes, in a sense, alien and alienating. This alienation compounds the sense of bodily dissociation that the subject invariably feels due to the totalizing model of bowel management that has already been imposed upon the body, a model, that is, that takes no account of the subject's personal needs, feelings, or body rhythms. Taken together, the techniques for managing incontinence reflect the subjugating effects of medical power and the extreme prioritizing of the corporeal over the psychological at the Otago Spinal Unit.

### *Maintaining the Integrity of the Skin*

The worst and most striking complication of combined motor and sensory loss is the pressure sore (or pressure area) [that] can occur sitting in a chair just as easily as sitting (or lying) in a bed.

—GILL CREEK ET AL., *Personal and Social Implications of Spinal Cord Injury*

A pressure sore occurs when the weight of the body cuts off blood supply to tissues underlying bony points of the body. The tissue subsequently

breaks down, leaving an ulcer that may take weeks, months, or even years to heal. Because pressure sores are septic, they are potentially life-threatening, as septicaemia can result if sores are left untreated. Thus, education about pressure sores begins early in the rehabilitation process: what they are, and how to avoid them. Graphic color photographs of fully blown pressure sores are deployed: angry, gaping holes with pussy, rotting flesh, devouring as much as a whole buttock, sometimes both buttocks, the sacral area, or a heel. This is living death, shock tactics designed to show the contingency of the paraplegic body; something the paraplegic body-subject is never allowed to forget while in the spinal unit; something continually reinforced by the survival techniques taught: shift body weight often, take extra care when transferring from chair to shower, toilet, or floor for physio; check your buttocks, hips, and heels every night; rub any red areas with vitamin A ointment to restore circulation and nourish the skin; if an area has darkened past the red stage to black, breakdown is imminent—get off your backside immediately and stay on bed rest until normal color returns. This set of “body practices” (where “care of the body” is very much linked to care of the body in a clinical sense) inculcates in the paraplegic a new way of knowing his or her self that recalls Foucault’s discussion of how the need “to attend to oneself” and “to take care of oneself” (1997a, 93) has become a way to achieve self-knowledge, a way of knowing thyself.

In the Otara Spinal Unit, pressure sores are given a moral dimension. As such, they have implications for the subject’s sense of self, how others perceive that self, and how one’s character is read. At the spinal unit, medical professionals couch pressure areas in terms of “self-neglect,” rather than “body neglect.” The implications of the expression *self-neglect* are that the individual who has the pressure sore feels sorry for her/himself; that s/he is just plain lazy, incompetent, a no-hoper, wants attention, can’t hack it, is giving up. One has doubts about self, moreover, as one’s standard of self-care is called into question by other paraplegics, who generally buy into the medical, “self-neglect” scenario. This “buy-in” demonstrates the colonizing effect of medical power and its ability to create reality, to create subjects of a certain kind, with a particular subjectivity.

In this section, I have shown how totalizing techniques of body maintenance are imposed to produce a docile body, one that can be transformed and used. These techniques insert the paralyzed subject into the game of truth called “paraplegia,” a truth-game that is defined by medical discourse in which the body and self is experienced and understood in the terms and techniques of body maintenance; techniques that turn the subject back on its body, although in a distanced, disembodied, and mechanistic way; tech-

niques that are inscribed on the paraplegic body in order to produce a docile body and a governable, yet governing, subject—that is, a docile, paraplegic body-subject.

### *Medical Power and Resistance*



For Foucault, power relations are “mobile, reversible, and unstable.” Furthermore, there is no power without resistance, for power relations “are possible only insofar as the subjects are free” (1997b, 292). It would be wrong, therefore, to conclude from the foregoing discussion that, once inside the Otara Spinal Unit, patients became totally quiescent and uncritically accepting of normalizing medical expertise. While numerous bureaucratic rules were resisted, ignored, and broken, the struggle for control of the body was the context in which the fiercest resistance occurred. It was here, in the context of corporeal control, that the memories of former idiosyncratic, nonparalyzed bodies provided a reference point from which to resist, that is, where a slipping from one subject-position to another subverted a totalized, and totalizing, subject-position. In the following remarks, a man talks about his resistance to the imposition of impersonal regimes of bowel and bladder management:

You are going to go to the toilet every three days. . . . That is what is in the book, and that is what you are going to do. I said, “Like hell. I go everyday. This is the way that I went before my accident, why should I change now?” . . . And you have got to use a catheter, and you have got to do this, and that, and it’s all a load of crap because when I got outside, I just threw them all away.

One woman participant gave me a harrowing account of her resistance while she was still in the spinal unit:

I was on intermittent catheters . . . [but] was adamant I had to have an indwelling catheter as . . . I had a really bad UTI [urinary tract infection]; and the way . . . you get rid of an UTI is to push fluids; and you can’t push fluids if you’re on intermittent catheters. So I said, “Give me an indwelling catheter until I get rid of my UTI.” And they said, “No.” . . . I just stole one and put it in and they got really upset and took it out in my sleep. . . . They thought that it was fine that I was spending my entire life pissing, showering, changing. And that’s all I had time for. I was

absolutely suicidal. I was just *so* low. . . . I will not ever be subjected to that . . . again.

This resistance is as much about the rejection of authoritarianism as it is about stating corporeal ownership, of the subject reclaiming its body, of feeling comfortable with its corporeality, asserting its own authority over its own body. This is not to say that the individuals with whom I spoke rejected all medical expertise. To the contrary, only the totalizing aspects were strongly resisted; positive, productive aspects were assimilated as necessary, life-enhancing techniques. Since we are all embodied selves and enselved bodies, there will always be a trace of what has been done to our bodies, especially by our selves, which molds and creates us as subjects.

*Docile Body-Subjects: The Ongoing Effects  
of Body Maintenance*



For most of the paraplegics with whom I spoke, their paraplegia, their sense of self, and their lives are not measured in terms of good or bad as much as in terms of difference, that is, of being different. It would be idle speculation to dwell on what might have been: one must live in the present of what is, live the paraplegic body from one moment to the next. Ultimately, this involves the organization of one's life around the demands of bodily maintenance. The following quotes from two participants illustrate how living their paraplegic bodies has not only changed the way in which they live their lives, but also how living these bodies has changed the ways in which each of them perceives their respective selves:

You gotta look after yourself. I don't think about it all the time, but you gotta be aware of pressure areas and things that may go awry. I suppose you become more aware. Yes, I mean, since I've been in the chair, I've become more aware of the body, what it can tell me. . . . I just don't take it for granted. If something goes wrong, maybe [you] get some spasm, it'll tell you.

While paraplegia does not dominate this paraplegic's sense of being, he is always aware of his body, its special needs, and adjusts his behavior accordingly. Similarly, the confidence and control that the next participant exudes is underpinned by a disciplined and conscious monitoring of the body.

I think of my body as a baby now, and I'm the mummy. In my brain, I have to think about and worry about it. How I'm sitting. . . . I have to think for my bodily functions, when I go to the toilet, what time I do it, how often, whether or not I'm sitting on an object and getting a pressure area. I worry about my kidneys. Drinking fluids, you know. I just generally am in tune with my body.

This subject has to know more about his body, precisely because it does not work. And it is in that lack of function that he forges identity. He continues:

It's a bit of a drag really. I hate . . . it's always a time for a reflection on the fact that you're a cripple. It's a constant reminder that you are paralyzed, because otherwise you just wake up in the morning and jump in your wheelchair and it really doesn't matter that you're in a wheelchair or not. . . . It's not until, say, in a pub, I've got to go and pass a catheter [to] have a piss. . . . And you've got to do it all in a certain way. You've got to have sterile, clean conditions, and it starts to manipulate your life. Your body dictates to you and it's always a reminder that you are different. Those are the things that keep you different; otherwise if you . . . had all your bodily functions—pissing, shitting, and coming—and you were in a wheelchair, really, in the end, it would make no difference that you couldn't walk.

### *Conclusion*



In this chapter, I have employed a Foucauldian approach in order to consider the rehabilitation of paraplegics in the Otara Spinal Unit. Using Foucault's notions of biopower, normalization, and the carceral, from his work on coercive practices and the relationship between the subject and games of truth (1977, 1979, 1980a, 1980b), I have argued that in the rehabilitation unit medical power is deployed in order to produce a certain type of body and a certain type of subject: a docile body and a governed and governing subject—in other words, a docile paraplegic body-subject. This is a body that is able to be “used, transformed, and improved” by virtue of the fact that its subject governs techniques of bodily maintenance. This body simultaneously governs the embodied subject. For without a docile body, the coherency, the life of the paraplegic body-subject would cease.

The transformation begins in the spinal unit with the impersonal and



seemingly arbitrary application of disciplinary body techniques, which compound the effects of motor and sensory impairment in ways that induce important changes in self-perception. The concretization of what Foucault (1980c) calls the power/knowledge nexus and the realization of the disempowering effects of paralysis precipitate that first change: spinal unit staff have the knowledge about paraplegia and are in a position to do things to the paraplegic body, to *my* body, to *my* self! As I have shown, the imposition of regimes of treatment that took no account of participants' individuality and individual needs challenged their sense of "self" as these regimes redefined them entirely in terms of the(ir) paralyzed body, and socialized them to become "paraplegic." A number of participants in my research said that they felt as if their bodies were the raw material in a factory process devoted to churning out "rehabilitated paras." The "objectification" of the body that begins with the manual self-care that the body now demands, compounded by the production-line approach that is used in the spinal unit to inculcate techniques of bodily maintenance, entails that the relationship between subject and body is changed. This is the second change to self-perception that these techniques precipitate. Living has become very much tied to consciously maintaining an objectified paraplegic body, which largely determines what, when, and how the paraplegic subject does things with its life.

While the transformative effect of medical power was resisted by many during their stay in the spinal unit, none of these subjects could escape the reality of their bodies, their paralysis, and the truth-game of paraplegia that had been learned in the Otara Spinal Unit (though that truth-game was often modified upon discharge from the unit). To survive, these subjects must continually be aware of keeping their bodies docile. In short, they have become paraplegic body-subjects.<sup>4</sup>

#### NOTES

1. The OSU is a specialized rehabilitation unit attending exclusively to spinal-cord-injured people. While both paraplegics and quadriplegic undergo rehabilitation here, this chapter focuses solely on paraplegic rehabilitation.

2. A number of feminists have, from a poststructuralist perspective, developed the notion of multiple subject positions, multiple selves, or multiple identities (see, for example, McTige Musil 1990; Kondo 1990; Sawicki 1991; Kennedy, Lubelska, and Walsh 1993; Haber 1994; and Munford 1995, in relation to women with disability). From such a perspective Kondo argues that identity "is not a fixed 'thing,' it is negotiated, open, shifting, ambiguous, the result of culturally available meanings and the

open-ended, power-laden enactments of these meanings in everyday situations” (1990, 24).

3. The spinal column consists of twenty-nine vertebrae that are divided into four groups to indicate the nerve supply they control. The eight cervical vertebrae (C1–8) control nerve supply to the diaphragm, arms, and hands; the twelve thoracic vertebrae (T1–12) control nerve supply to the chest and abdominal muscles; the five lumbar vertebrae (L1–5), the leg muscles; and the five sacral vertebrae (S1–5), bowel and bladder. Since paraplegia results from injury at the thoracic, lumbar, or sacral levels, the arms and hands are not affected by paralysis as they are in instances of quadriplegia that result from injury to the cervical vertebrae.

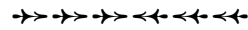
4. I would like to thank Mark Sherry, Gabrielle Rose, and Shelley Tremain for their constructive comments on various drafts of this chapter. Responsibility for its final content rests with me.

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NIRMALA EREVELLES



## Signs of Reason

### *Rivière, Facilitated Communication, and the Crisis of the Subject*

But all that I ask is that what I mean shall be understood.

—PIERRE RIVIÈRE

On June 3, 1835, in the village of la Faucterie, a young man named Pierre Rivière brutally murdered three members of his family, actions that he justified with a memoir that served as testimony to his sanity—an event that inspired Foucault’s text, *I, Pierre Rivière, Having Slaughtered My Mother, My Sister, and My Brother*. In this text, Foucault juxtaposed legal and medical testimony from the ensuing trial with Rivière’s explicit memoir in order to explore how power structures and social institutions in nineteenth-century Europe collaborated in bringing to birth “the psychiatrization of law, the medicalization of crime, and the therapeutization of justice” (Szasz 1975). By offering a microanalysis of this case, Foucault’s text exposes “the chaos of values and beliefs, of knowledge and power” (Kurzweil 1975) that emerged out of the battles that took place between the medical experts and the judicial body in their attempts to ascertain whether the author of this “insane” crime could also be the author of a lucid and coherent text. After all, how could someone who was believed to be the “village idiot” demonstrate an ability to write and reason?

More than a century later, a similar “chaos of value and belief” has arisen in the field of special education in regard to the educational definitions of autism and mental retardation. In 1990, Douglas Biklen, a noted scholar and advocate for persons with disabilities, published an article in the *Harvard Educational Review* entitled “Communication Unbound: Autism and Praxis,” in which he reported on the unexpected literacy that students who are labeled autistic or mentally retarded demonstrate when they are

assisted by an augmentative communication system called “facilitated communication.” Facilitated communication involves the provision of physical and emotional support to individuals with “severe” communication impairments as they type, or as they point to letters or pictures on a communication board. Biklen and his fellow researchers have claimed that the physical support offered through facilitated communication enables these individuals to overcome the physical challenges that interfere with their ability to perform certain motor tasks (Biklen and Cardinal 1997). In other words, when individuals who previously had been perceived as severely developmentally disabled used techniques of facilitated communication, that is, when facilitators provided varying degrees of physical support to these individuals, they expressed sophisticated thoughts. It was not long before Biklen’s report attracted the attention of several critics who argued that Biklen’s assumptions contradicted, and possibly ignored, scientific evidence (see Shane 1994; Spitz 1997; Twachtman-Cullen 1997). These critics pointed out that since medical and scientific evidence has shown that students with autism or mental retardation have not been able to communicate on demand, it should follow logically that they are incapable of a whole host of simple and complex performances (Shane 1994). Critical of the subjective approaches of qualitative research that Biklen and his colleagues offered as proof of the effectiveness of facilitated communication, these critics argued that when facilitated communication was subjected to objective, rigorous, and controlled experimental testing, it failed to meet scientific criteria of validity (who is the real author of these communications?), reliability (how consistent are these communications?), and generalizability (can these tasks be performed on demand in different situations?). To further complicate matters, some court cases, which were initiated when a few young adults who had used facilitated communication made unsubstantiated allegations of sexual abuse, triggered additional inquiries into the legal issues concerning the authenticity of authorship that the facilitation involved. Because of this turn of events, Biklen and his colleagues were accused of supporting and propagating inappropriate medical-educational treatment of students who had been labeled autistic or mentally retarded, and of violating ethical standards.

In this chapter, I argue that both of these controversies foreground the crisis of the humanist subject. That is, I argue that the “chaos of value and belief” that these two controversies have generated bring to bear seemingly simple questions: Are people who have been identified as cognitively disabled competent (or incompetent) to represent themselves? Is it possible that these people can have observable physiological, cognitive,

or behavioral disabilities, but also exhibit behavior and thinking that could be termed “normal,” that is, rational? Or, to put it in more philosophical terms: How should one explain these contradictions in the face of the humanist premise that we all inhabit autonomous, rational, stable, and coherent subjectivities?

I will begin the chapter with a discussion of the crisis of the humanist subject in the current context of poststructuralism. In particular, I focus on the poststructuralist depiction of the humanist subject as a fiction, which I argue becomes apparent in the debates around the authorship and competency of persons with disabilities as represented in both Rivière’s murder trial and the facilitated communication debate. In other words, I argue that the salience of both the Rivière case and the facilitated communication controversy extends beyond questions of authorship and competency to questions about how and why particular kinds of knowledges are formed, how they interact with certain institutions (such as law and education), and the roles that are prescribed to them (for instance, as the assessors of competence and incompetence).

*Incoherence in the Age of Reason:  
The Crisis of Subjectivity*



It is now common knowledge that the Enlightenment ideal of the rational, coherent, unified, and stable humanist subject has come under considerable critique in the context of poststructuralism. Poststructuralists have theorized the subject as an effect of language. This stance with respect to the subject makes radically different assumptions than the humanist stance on the subject according to which the subject is capable of fully representing him- or herself through the transparent medium of language. Rejecting the humanist allegiance to the existence of transcendental signifiers (such as Self, Truth, Reason) that exist outside the play of differences, poststructuralists have argued that language is constituted via the play of multiple signifiers. Therefore, the subject, who comes into being through language, is a product of partial, multiple, and unstable meaning systems. Jacques Derrida has argued, for example, that “the subject . . . is inscribed in language, is a ‘function’ of language, becomes a speaking subject only by making its speech conform . . . to the system of the rules of language as a system of differences” (1995, 116).

Notwithstanding his protestations to the contrary, it is in this philosophical tradition of poststructuralism that Foucault is generally consid-

ered to work. For Foucault, the primary objective of philosophical inquiry should not be the investigation of the history of ideas, but rather should be the examination of how human beings are constituted as subjects (Foucault 1983). As Foucault puts it: “The individual is not a pre-given entity, which is seized on by the exercise of power. [Rather] the individual, with his identity, is the product of a relation of power exercised over bodies, multiplicities, movements, desires, forces” (1980, 73–74). Insofar as Foucault maintains that subjectivity is not an originary force, not an originator of speech acts and ideas, but rather is the constituted effect of knowledge regimes (discourses), he argues for a genealogical analysis that would reveal that what lies beneath the constructed unity of the subject (for example, reason or consciousness) is not a point of origin, but rather “dispersion, disparity, and difference, and the play of dominations” (Smart 1983, 59). Thus, what we are left with is not the stable, rational, unified subject of Enlightenment thought; on the contrary, what accosts us is the bewildering specter of incoherence.

This specter of the incoherent subject who stands in radical opposition to the coherence of Reason comes alive in *I, Pierre Rivière, Having Slaughtered My Mother, My Sister, and My Brother* (one of Foucault’s works that is seldom cited). In this text, Pierre Rivière actually embodies this incoherency, such that to some people he appears as a “savage not subject to the ordinary laws of sympathy and sociability” (Foucault 1975, 11), while to others he appears to exhibit “a great aptitude for the sciences, a lively and strong imagination coupled with an eagerness for instruction and the achievement of glory” (45). The recognition of this incoherency is based on the assumption that Foucault describes in *Madness and Civilization*, where reason and madness are constituted as binary opposites that appear to be immune to exchange, and “as though dead to one another” (1965, ix). Foucault traces this construction of madness and reason as binary opposites to the emergence and development of new forms of knowledges and new institutional techniques of exclusion and confinement that emerged out of the social, economic, and political context of the Enlightenment. In fact, it is this very context that sets the backdrop against which the bizarre drama of Rivière’s life unfolds.

The drama begins at the point when Rivière, a twenty-year-old peasant from the commune of Aunay, is arrested for the brutal murders of his mother, sister, and brother, committed a week earlier because, as he claimed, “God ordered me to do what I did” (Foucault 1975, 10) in order to “deliver him [his father] from an evil woman [his mother] who had plagued him continually ever since she became his wife” (22). Faced with the extreme

brutality of the crime, the courts, the doctors, and the public were left to struggle with the dilemma of reading Rivière either as “the monster of our time” (8), or as someone who had committed this monstrous act due to some form of “mental derangement.” Documented in the *Annales d’hygiène publique et de médecine légale* in 1836, the case was comprised of several medical reports that arrived at contradictory conclusions, as well as a fairly large collection of court exhibits that included witness statements that appeared to inadvertently collaborate with each other in the construction of Rivière as either completely insane or completely rational.

The machinery of the criminal justice system that aimed to indict Rivière sought to demonstrate that his crimes depicted the workings of a coherent subject of reason. While the prosecution sought to portray Rivière as a “rational” criminal, medical evidence emerging from the recent, and burgeoning, field of psychiatry interpreted the “facts” that the prosecution presented as ones that reached conflicting and contradictory conclusions, to the extent that these “facts” began to weaken the prosecution’s case, as well as to confound the jury. On one hand, Bouchard, a general practitioner, and the only doctor who actually examined Rivière, recorded that “[h]e shows every sign of a bilious-melancholic temperament,” but “[n]othing in his answers indicates any derangement of the mental faculties” (Foucault 1975, 122–23). On the other hand, Castel, who was assistant head physician at the Bon Saveur asylum at Caen, and expert witness for the defense, drew on “a wholly specific semiology of madness” (Castel 1975, 158) to discredit Bouchard’s diagnosis and to argue that Rivière’s disparate behaviors were in fact indicative of a mental deficiency that may have existed since his early childhood.

Privy to these debates, members of the local community also offered their readings of Rivière’s character, readings that were *shaped to fit* the heinous/insane nature of his crime. For instance, several of these witnesses reminisced about some of Rivière’s strange habits—his obstinacy, his taste for solitude, and his “bizarre” behaviors of talking alone and making strange gestures, producing unmotivated and unprovoked laughter, exhibiting a cruelty to both animals and children, and declaring an aversion to women—and interpreted these habits as “signs” of insanity. Only the parish priest of Aunay, one Jean-Suis Ruiray, was skeptical of the construction of Rivière as insane. Ruiray pointed out that although Rivière “seemed to have a skew in his imagination[,] . . . [c]ertainly no one would have thought anything more of it had it not been for the murders he committed” (Foucault 1975, 26).

With the jury facing such conflicting testimony, both the doctors and the



lawyers were eager to examine Rivière's memoir, since they believed that the truth of madness finds expression in the madman's speech. They assumed that Rivière's memoir, taken to be the transparent (and real) representation of his subjectivity, would resolve the controversy regarding his (in)sanity. This certainty dissipated, however, when in Rivière's memoir the "frontier between rationality and madness [was] hard to establish." In addition, the memoir "seem[ed] to have brought once again to the fore the dangerous question of the coexistence of madness and rationality, of partial delusion and lucid interval" (Fontana 1975, 272–73).

Rivière, himself, made claims to a rational and coherent subjectivity through his memoir when he wrote: "I thought I should be like other men" (Foucault 1975, 108). To "be like other men" required, however, that Rivière accept the daily contradictions of peasant life in rural France, caught within the cataclysmic transformations that followed the Revolution. As a result of these transformations, the old feudal order had been demolished. Nevertheless, the peasants continued to experience exploitation within the new order of a liberal society that perpetuated the old hierarchies and inequalities, albeit now under the false pretenses that these social relations were voluntarily accepted by all members of society. In the Rivière case, these contradictions of free men in a free society manifested themselves in the daily tribulations that Rivière's father suffered at the hands of his wife due to certain disputes over the legal contracts of marriage, property, and inheritance that had come to be used to secure people in their place in life. And though the senior Rivière attempted to publicly draw attention to the injustices of these contracts, the only response he received was ridicule. As Jean-Pierre Peter and Jeanne Favret explain it, "[I]n a world now subject to the abstract violences of money, the peasant and his like, the native after the conquest, were henceforth defined only as the negative of the ascendancy" (1975, 181). Rivière, the son, observing his father's distress, resisted this form of debilitating subjectivity that was imposed on him. Thus, in the memoir, the younger Rivière wrote:

I esteemed myself far better than others. . . . I thought I would raise myself above my condition. . . . I knew the rules of man and the rules of ordered society, but I deemed myself wiser than they. . . . I thought that it would be a great glory to me to have my thoughts opposed to all my judges, to dispute against the whole world. (Foucault 1975, 102–8)

Rivière (the son), therefore, planned to murder his mother, his sister, and his brother, in an attempt to sever the links that bound his father to the

tyranny of the contract. The younger Rivière also believed that committing these murders would provide him with the opportunity “to raise myself, that my name would make some noise in the world, that by my death I should cover myself with glory, and in time my ideas would be adopted and I should be vindicated” (108).

These dreams of immortality and glory were not to be realized, however. Rivière, notwithstanding his articulate, rational, and coherent memoir, could not surpass the imposed construction of himself as peasant who, though having access to the formal equality of rights, continued to be regarded within the new social order as beast or thing, as “something close to nothing, who could not seriously be thought to have anything to say” (Peter and Favret 1975, 187). With the incidence of the murders (the only “voice” to which Rivière had access, and which put him outside the pale of civil society), it became impossible for the lawyers and the doctors to arrive at consensus on whether Rivière’s memoir was a coherent reflection of sanity or insanity: the document only highlighted the conflicted aspects of a subject rendered incoherent by social, political, economic, and personal pressures. This incoherence was unacceptable in the Age of Reason, which required answers that were based on the irrefutable “proof of the true and the false” (Fontana 1975, 285). And so, rather than accepting the conflicted subject, rather than reading coherence as wholly illusory and fictional, Rivière’s memoir was subjected to several contested readings that cohered in an unlikely way so as to distance it from the transcendental signifier—Reason.

*“What Is an Author?”: Facilitated Communication and  
the Question of Agency*



In this section of the chapter, I map connections that can be drawn between the Foucauldian critique of the humanist subject, as exhibited in the Rivière dossier, and the debates surrounding facilitated communication for people with autism. As I mentioned in my introduction, the facilitated communication debate foregrounded the possibility of inconsistencies in the official definition of autism and, in doing so, threatened the truth-claims of a positivistic science. Experts in the study of autism have associated autism with “problems of speech, language, and communication, including mutism, echolalia and perseverative speech, difficulties with social interaction, stereotyped activity, a seeming concern for sameness and constancy of order, and a lack of response to external events or actions” (Biklen 1993,

15). Notwithstanding this impressive list of identifiable behaviors, there has been little consensus about the “true” nature of these behaviors and their implications for the people who are labeled as autistic. Moreover, the coherency of this disability category has often been called into question because some people “with autism” are thought of as savants (that is, people “with mental retardation” who, in one or more skills, demonstrate proficiency above the level expected of individuals “without mental retardation”), while other people with autism are labeled as “severely developmentally disabled.” In fact, the only connective strand that holds the incoherencies of the category together has been the consistent association of autism with abnormality and deviant difference. And it is precisely here that facilitated communication complicates matters.

Facilitated communication is a technique in which a facilitator holds the hand, wrist, elbow, or shoulder of a person with a disability as s/he constructs messages by typing on a keyboard or by pointing to letters on an alphabet display. The method was first described in a book entitled *Annie’s Coming Out*, a collaborative effort by Rosemary Crossley, a teacher in Australia, and Annie McDonald, a young woman who had been diagnosed with an athetoid form of cerebral palsy (Crossley and McDonald 1980). McDonald, who had been institutionalized right up until the time that she went to live with Crossley, was discharged amid much controversy and litigation. The legal disputes arose when the Supreme Court of Victoria, Australia, ruled that McDonald’s ability to communicate through facilitated communication was “authentic,” and that there were distinct possibilities that she possessed “normal” intelligence. Even after Crossley and McDonald had won their case, however, and several people with disabilities had begun to use facilitated communication, the controversy did not die down. Scientists argued that the possibility of facilitator interference called into question the authenticity of these communications. In the late 1980s, the venue of this debate shifted to the United States, where Biklen had introduced the technique. News about facilitated communication spread like wildfire, especially when children with autism who had previously been withdrawn and uncommunicative were seen to exhibit a high degree of literacy. Evan, a fourteen-year-old student with autism, used facilitated communication to describe what the ability to communicate meant to him:

It [facilitated communication] can treat us to the world’s respect and warmth . . . freedom, friendship, and confidence . . . freeing me from the frightful triangle of fear, frustration and failure. I want to help autistic

people everywhere find reason and release. Positive reassurances and responses were white waters in dark tides of terror. (Biklen 1993, 189)

While Biklen used quotes like the one above to argue that disability was indeed a social construction, his critics countered these claims by arguing that facilitated communication was being used as “a vindication for the disability rights movement” (Twachtman-Cullen 1997, 3). The critics also argued that facilitated communication would suffer a similar fate to that of the historical exposition of the Clever Hans syndrome, the Ouija board, and witch stick, that is, would be exposed as nothing other than the unwitting instruments for the expression of ideas, wishful thinking, and inner conflict. These debates came to an ugly head when several students with autism who had been using facilitated communication for some time alleged that a parent, a teacher, or a caregiver was sexually abusing them. When medical and other evidence did not corroborate some of the charges, the courts ordered that empirical evidence be submitted to prove the authenticity of the communication. In the ensuing controlled, “double-blind” experiments, in which the facilitator and the client were flashed similar or different pictures to test word recognition independent from the facilitator, almost all of the students with autism failed to pass the test. The results of these tests were broadcast on several news shows that had previously hailed facilitated communication as a “miracle.” In response to these procedures, Biklen and his colleagues who support facilitated communication have critiqued the test procedures and have argued for more naturalistic (qualitative) modes of inquiry. In addition, other professionals in the field of autism have argued that the results of these tests only prove that facilitated communication has violated conventional knowledge about autism’s severity, chronicity, and symptomatology.

Notwithstanding the differences in the events that occurred, and the different historical periods and social contexts in which these took place, I contend that both the Rivière case and the facilitated communication debate are brought to crises when faced with the similar requirement of defining coherence of the “deviant” subject according to positivist rules and humanist rationality. In both cases, different parties struggle over the constructions of reason and unreason as distinct and separate categories in an attempt to maintain the coherency of the conflicted and fragmented subject. Like the Rivière case, moreover, the facilitated communication debate involves dissenting parties struggling among themselves to offer a definitive response to another Foucauldian question: What is an author? (Fou-

cault 1977). In other words, what undergirds the conflict in both the Rivière case and the facilitated communication debate is that all of the parties (notwithstanding their conflicting positions) are invested in the construction of the author as humanist subject.

In his famous essay “What Is an Author?” Foucault argues that the construction of “the author” is not a simple attribution of a discourse to an individual, “but is evolved from a complex operation whose purpose is to construct a rational entity that we call an author” (1977, 127). In this context, the author is believed to display a principle of unity in his or her writing such that “contradictions are resolved, where the incompatible elements can be shown to relate to one another or to cohere around a fundamental and originating contradiction” (128). As Toril Moi has pointed out, moreover, “the text becomes nothing but the ‘expression’ of this unique individual [the author] . . . a mere window onto the self and the world, with no reality of its own” (quoted in Burke 1998, 42).

My argument is that in both the Rivière case and the facilitated communication debate the desire to promote a humanist definition of authorship plays an important role in the attempts to settle the consequences of certain legal issues and scientific knowledges. In the case of Rivière’s memoir, the assumption that the text would be the window of the self in relation to the world prompted both the doctors and the lawyers to make the memoir central to the murder. Rivière’s memoir did not, however, support this principle of unity that had traditionally been ascribed to the author as rational man. Fontana argues that “the whole Western metaphysic of the discourse of reason never appears in Rivière’s discourse; instead, what appears in it is a continual and indefinite ‘doubling back’ from one term to another,” which entails that the text can neither support a coherent image of rationality nor deny it (1975, 286). It is because of this “continual and indefinite doubling back” that the notion of Pierre Rivière—as “author”—gets called into question.

While the issue is essentially the same in the facilitated communication debate, it is constructed on slightly different terms. Here, the presumed “author” (who in this case is the person with autism) has already been assigned to the space of unreason (disability) and is compelled to reclaim for itself the role of rational subject by demonstrating personal autonomy as the author. Indeed, several persons with autism who use facilitated communication have poignantly portrayed the costs that accrued to them because they are not recognized as autonomous and rational subjects. For example, Biklen cites the writing of seven-year-old Mark, who expressed the following sentiments through facilitated communication:

I WANT TO BELIKE NORMFAL KIDDSS. AHBLE TO TALLK . . .  
I AIDON'T WANT TO BE AUTISTIC . . . NOBODY REALLY  
ZUNDSERSTANDS WHAT IT FEELS LIKE, IT IS VERY LONELY AND I  
OFTEN FEEL LOUSY. MY MOOD IS BAD A LOT. I FEEL LESS LONLI  
WHEN I AM WITH KIDS. . . . I AM VERY UPSET BEC I NEED FA  
CILITATION. I DON'T WANT TO DEPEND ON PEOPLE. (1990, 162)

From the excerpt above, it would appear that Mark, though only seven, is well aware of the consequences of demonstrating his autonomy. When confronted with this message, many critics of facilitated communication have been skeptical of the authenticity of this authorship. Referring to the prevalent clinical knowledges about autism, they would argue that Mark might not be the author of the text; rather, a facilitator who is unconsciously influencing a client could have authored the text. Arguing that no person is too physically disabled to be unable to communicate, and that thousands of nonverbal people have been (and are) able to express themselves independently with other technologies, the critics of facilitated communication have questioned why persons with autism depend on another person to hold their hands while they communicate. For instance, in an interview on the Public Broadcasting System news program *Frontline*, Howard Shane, who is the director of the Communication Enhancement Center at Boston Children's Hospital, had this to say about the written output of users of facilitated communication:

The outcomes that were being reported were just so far out of line with what anyone had ever found. They are communicating in grammatically complete sentences. They're marking the tense correctly. Their spelling is accurate. They have insights that go far beyond their years.

In making this sort of argument, the critics of facilitated communication also invoke the ideal of the humanist subject—rational, coherent, and above all autonomous—as the impossibility that haunts persons who are labeled autistic, at least in the context of authorship. In fact, from 1989, several tests were devised that included naming pictures of common objects, matching pictures by shape and color, and even asking personal questions about persons with autism in pre-test and post-test trials. In all of these tests, whenever the facilitator was not exposed to the same information as the client, the responses were completely wrong. In the face of this overwhelming scientific proof, Twachtman-Cullen, another critic, actually describes facilitated communication as an assault on the subject by claiming that

ability to communicate thoughts, ideas, and intentions is humankind's most complex multifaceted, and genuinely awesome achievement. Leaving the power of communication in the hands of the facilitator is never acceptable if there is any doubt regarding authorship, especially if the client is barred from using any communication means other than Facilitated Communication to protest against the words and thoughts that might not be his own. (1997, 167)

Ironically, Biklen and his associates, while disagreeing with their critics, invoke the same logic of humanism to articulate the argument for facilitated communication. In *Communication Unbound* (1993), Biklen's first book on facilitated communication, he makes a promising start by interrogating the notion of autonomy and defining it in different terms than the critics. In *Contested Words, Contested Science* (Biklen and Cardinal 1997), a book that Biklen coedited, he and his colleagues appear to concede the validity of traditional definitions of autonomy, and only go so far as to suggest that alternative methods should be used to verify the autonomy of authorship. For example, Biklen begins by arguing that the notion of absolute autonomy or independence is itself contested, because even though nearly every person is forced to rely on others in nearly every aspect of their lives, there are only certain types of interdependencies (such as eating, hygiene, mobility, and of course facilitated communication) that are used as evidence of dependence. Having made that remark, Biklen, rather than expose the humanist construction of subjectivity as a fiction, merely rearticulates an alternative definition of the humanist subject by arguing that "when people with disabilities speak of . . . independence in communication, they do not necessarily mean doing things apart from facilitators or attendants, but rather enjoying what other people take for granted—to make choices about everyday matters, the chance to express themselves, and the opportunity to participate at the very center of society rather than at its margins" (Biklen and Cardinal 1997, 187). In a continuation of this tradition, in *Contested Words, Contested Science*, Biklen locates the humanist subject as central to the discourse and succumbs to the pressure to uphold traditional notions of autonomy, at least in authorship, by attempting to replicate, through both positivistic and naturalistic methods, the experiments that test independence in communication.

The installation of the humanist subject/authentic author as central to the facilitated communication debate is problematic, especially after the post-structuralist depiction of the subject as a humanist fiction. In a similar vein, poststructuralists have also called for the death of the author. Thus, for exam-

ple, Roland Barthes offers a critique of traditional literary criticism where “the explanation of a work is always sought in the man or woman who produced it, as if it were always in the end, through the more or less transparent allegory of the fiction, the voice of a single person, the *author* ‘confiding’ in us” (1995, 77). If, as the Rivière case demonstrates, the subject is itself a fiction constantly being (re)configured by multiple and competing discursive arrangements, what allows us to persist in our treatment of the “author” as something that has a prediscursive essence of being? Perhaps it is because, as Bronwyn Davies, drawing on Mikhail Bakhtin, argues,

language is spoken not only *as if it* were one’s own—but in speaking is taken on as one’s own. One’s words carry the accretion of other’s past usages but are not recitations—rather they are the available fabric with which each person does being as a member of the various collectives in which they participate in their own particular way. (1990, 342)

While Davies’ argument is effective in challenging the notion of autonomy that is considered as integral to authorship, Barthes further extends this argument to demonstrate that, in fact, the author/subject is itself reconstituted in the very instance of writing: “The author is nothing more than the instance of writing just as I is nothing other than the instance of saying I: language knows a ‘subject’ not a ‘person,’ and this subject, emptied out of the very enunciation which defines it, suffices to make language hold together, suffices, that is to say, to exhaust it” (1995, 78). Barthes’s idea in this context echoes the Foucauldian claim that the subject is both the object of knowledge and is simultaneously capable of (re)constituting knowledge itself.

Given that the humanist construction of the author has been subverted by the poststructuralist conceptualization of the “subject-in-process,” this critique holds interesting implications for my discussion of facilitated communication. For the subject is now “free to change, to insert itself within textuality without acquiring the transcendental solitude of the epic author . . . [and in doing so] . . . acquires revolutionary potentialities within discourse precisely because of its motility, its ability to take up new and transgressive subject positions” (Kristeva, quoted in Burke 1998, 50). For example, in the case of persons with autism who use facilitated communication and are assisted not only by the human facilitator but also by Canon communicators, computers, portable typewriters, and other sophisticated communications devices, the normative discursive structures that define autonomy and subjectivity in humanist terms are radically disrupted. This



disruption occurs because the dependence of persons with autism on such technology blurs the boundaries between human beings and machines in order to redefine the subject in the image of the blasphemous and transgressive cyborg: “a hybrid of machine and organism, a creature of reality as well as a creature of fiction” (Haraway 1990, 191). In such a context, the question of autonomy is no longer central in the facilitated communication debate, since, according to the new cyborg politics, assistive communication devices (whether machines or human facilitators) can now be perceived as “prosthetic devices, intimate components, multiple selves” that are instrumental in destabilizing humanist notions of subjectivity to make a place for the transgressive hybridized subject-in-process. When we invoke this poststructuralist depiction of the autonomous, rational, and stable subject as a humanist fiction, “What matter who’s speaking?” (Foucault 1977, 138).

### *Conclusion: Looking Behind the Silence*



Thus far, I have supported the poststructuralist critique of the humanist subject. I am, nevertheless, uncomfortable about ending this essay with Foucault’s murmur of indifference: What matter who’s speaking? It should matter to us who is speaking, because otherwise we would leave unanswered the critical question of agency and its relation to social transformation. In fact, in both case studies, the manner in which the question of agency was resolved had dire consequences for the key figures in both disputes. For example, in the Rivière case, because the courts could not determine the authenticity of authorship, Pierre Rivière was sentenced to life imprisonment rather than the death penalty, a decision that he resented and that, therefore, caused him to ultimately commit suicide. When facilitated communication, as the means of communication, was removed from some persons with autism, many of them were denied participation in the daily activities of their communities, and were instead returned to segregated settings. In short, in light of the poststructuralist critique of humanism, the challenge becomes how to retheorize agency without reproducing traditional notions of essentialized subjectivity.

This challenge is especially significant to persons with disabilities who have historically struggled in the disability rights movement to reconstitute for themselves empowering subjectivities, as the struggles for self-advocacy and the right to independent living demonstrate. In fact, Evan and Mark, both of whom have been labeled as autistic and whose words are

quoted above, can be seen as committed to reclaiming individual agency and reconstituting their subjectivities in humanist terms. In this context, therefore, it is quite possible that persons with autism would view with some suspicion (as a number of feminists have in the past) the theoretical move to undermine the ontological status of the subject and proclaim it to be a fiction, at the very moment when they have made counterclaims for their subjectivity (see, for instance, Mascia-Lees, Sharpe, and Cohen 1989). For example, bothered by the criticism that facilitated communication did not represent authentic communication, one of Biklen's collaborators, Eugene Marcus, who is a person with autism, collaborated with his friend and facilitator Mayer Shevin, to determine the level of support Marcus would need to prevent unconscious cueing on the part of the facilitator (Marcus and Shevin 1997). After having successfully passed the test, Marcus's response to those who might have asked him to prove that he actually wrote the chapter was: "I can't. But neither can anybody else who submits a chapter to an editor" (Marcus and Shevin 1997, 134). While on one level, Marcus's response seems to echo the poststructuralist theorization of subjectivity and authorship, in the final instance, Marcus's commitment is not to the poststructuralist notion of the fictional subject, but rather to humanist notions of rational and autonomous subjectivity.

Notwithstanding the above observation, I want to argue that it is no longer theoretically feasible to return to the humanist conceptualization of agency after poststructuralism's compelling critique. I am, nevertheless, critical of the poststructuralist move to retheorize subjectivity only at the level of discourse, where the mobile, transgressive, posthumanist subject is free to change and insert itself within textuality as if unaffected by social structures (Erevelles 2000). In fact, I will demonstrate that in both of the case studies, the critical question of agency is complicated by the politics of class in their respective historical contexts. It is for this reason that I propose an alternative way of analyzing these two case studies, one in which the focus is on the critical dialectical relationship between the subject and social structures within the specific historical contexts in which they occur. As I have argued elsewhere (Erevelles 2000), such an analysis will support alternative ways to bring about social transformation.

The Rivière murders occurred in the specific historical context that marked the shift from a feudal society to a capitalist society, where the fights for legitimation of the notions of the "free subject" and the "free market" were for the first time fought. It is in this historical context that Rivière's memoir vividly exposed how the interpellation of the "free" subject into the "new" ideologies was constantly challenged by the harsh material real-

ity of peasant life that in turn served as the means of subverting the idealized vision of freedom that capitalism supported. That is why Rivière's memoir, which details his reasons for committing the three brutal murders, could not be read as a text that had been produced by rational man: if it had been, it would (for a brief instant) have exposed the brutality of the "new" capitalist order.

A similar argument could be made when we locate the facilitated communication controversy within the current context of late capitalism. Indeed, what Fredric Jameson has described as the "cultural logic of late capitalism" has done little to transform the exploitative logic of nineteenth-century capitalist culture and has instead supported the expansion of market relations to the extent that they have now intruded into almost every aspect of daily life. Late capitalism has in fact been particularly successful in institutionalizing the concepts of the "free" market and the "free" subject in the current consumer culture and, in doing so, has effectively obscured the exploitation that occurs with production processes. Not everyone is "free" to participate in the market. Instead, as I have argued elsewhere, capitalist ideologies justify the exclusion of particular populations from the world of work by claiming that these individuals lack particular social and technical characteristics that are desirable for the economy, and therefore constitute a surplus population (Erevelles 1996, 2000). Historically, this surplus population has included disabled people, elderly people, people who are illiterate, and the racialized underclass. It is to this population that some of the users of facilitated communication have been assigned and constructed as the clients and consumers of "special services," offered through the welfare state, who bear the stigma of being unproductive as a result of their nonparticipation in the market. Moreover, these ideologies have been further ratified through the construction of a biomedical etiology of "deviance" from which have been derived diagnostic techniques to identify these "deviant" populations, as well as to demonstrate the "natural" inferiority inherent in their respective differences (Gould 1981; Paul 1995; Erevelles 2000). It is within this context that disability plays an important role in the construction of disability/deviant difference as an ideological construction of capitalism that has been used to justify the unequal social divisions of labor in market societies.

Unlike the peasant Pierre Rivière, the users of facilitated communication enjoy class privilege—a distinction that separates them from most persons with disabilities who live under conditions of abject poverty. In fact, it is because of their class privilege that this population of persons labeled autistic had access to the sophisticated technologies as well as facilitators that enabled

them to communicate. Notwithstanding the difference in their class locations, however, by attempting to recreate themselves as autonomous and rational authors, both Rivière and the users of facilitated communication were united in their struggle to interpellate themselves into the ideological discourses that supported a bourgeois subjectivity. In addition, the poignant irony that became apparent in both of these situations was that the very ideologies that masqueraded as the salvation of these individuals were instrumental in relocating them to the very margins from which they had struggled to escape. This does not, of course, mean that persons with disabilities are merely pawns of these ideological structures. By critiquing these ideological structures, it is possible to expose their oppressive functions, and by doing so to also work collectively towards transforming them.

It is for this reason that, more than a century later, echoes of the Rivière case can be seen to manifest themselves in the facilitated communication debate. Indeed, one could argue that the demonstration of the unusual literacies of Rivière, as well as the users of facilitated communication, should be viewed as a challenge to the “objective” criteria used to exclude the surplus population from participating in the productive economy. In their varying ways, therefore, both the Rivière case and the facilitated communication debate can be seen as events that disturbed the dominant order of things by raising questions about the social, political, and economic organization of capitalist society. Without the notion of the “free” and “autonomous” subject, capitalism cannot justify the social and economic arrangements that it supports. So, when Rivière, as well as the facilitated communication users, resisted their interpellation into “deviant” subject positions by blurring the lines between reason and unreason, they threatened the sanctity of the “free subject” by exposing their exploitation and exclusion. And that is why it was necessary to reduce their resistant voices to silence.

While in one respect this discussion revolves around the philosophical debates that explore contemporary views of disability, in another respect it speaks to educational issues, especially those that pertain to students who have been labeled as autistic or mentally retarded: the “peripheral subjects” (Foucault 1980, 98) of the institution of schooling. Biklen and Janet Duchan have reported, for example, that students labeled with autism or mental retardation who use facilitated communication have demonstrated “a desire to disaffiliate with the label of retardation” (1994, 174), claiming that their other dysfunctionalities (echolalia, compulsive behavior, and so on) do not predict a lack of intelligence. How we understand these claims of competency in the face of “scientific” evidence to the contrary might entail that we

“treat a competent individual as incompetent and [therefore] work on skills that are beneath his or her ability” (Biklen and Duchan 1994, 182), or that we violate conventional knowledge about autism (Green and Shane 1994) and, in doing so, once again construct (in)appropriate education programs for these students. In this chapter, I have argued that in a manner similar to the nineteenth-century murder case, the controversy surrounding facilitated communication and its implications for the education of students with disabilities contests the truth of fact, truth of opinion, and truth of science as constituted within the historical context of capitalism. In fact, it is precisely the ideological discourses of disability, discourses that legitimate capitalist societies, that have enabled a debate that occurred in the nineteenth century to find its echoes among other voices of silence more than 150 years later.

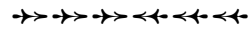
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SCOTT YATES



## Truth, Power, and Ethics in Care Services for People with Learning Difficulties

Foucault was concerned to understand how, within particular systems of knowledge, certain human acts, practices, behaviors, or characteristics emerge as specific problems. These “problematizations,” Foucault (1997a) contended, are dynamically linked to power and the formation of subject positions through which people become tied to a certain identity. Thus, his work is tremendously relevant to an understanding of the situation of individuals who, in some modern Western societies, are identified as “persons with learning difficulties.”

In this chapter, I demonstrate the promise of a Foucauldian approach to help us understand how power and governance operate in the community care accommodation for people with learning difficulties in modern societies. In particular, Foucault’s work can provide a framework with which to analyze the statements that people who use care services make about these services, an analysis that will enable us to build a picture of the forms of power that take hold of these people, subjectify them, and the ways in which they interact with these forces. This type of analysis provides a new set of criteria for understanding and evaluating community care services, criteria that are grounded in understanding how the people who are involved in these services negotiate the particular dynamics of power that direct their conduct and position them as subjects. Furthermore, this kind of analysis presents the possibility of finding new ways in which to look at care services and to work through the problems that they present to the people who use them. After a brief discussion of the concept of community care, we will consider how Foucault’s work encourages us to think in new ways about learning difficulties. Then we will turn to briefly examine an example that explores the merits of this new approach.



*Community Care*

In the United Kingdom, there is a concern that policy that relates to people with learning difficulties should be guided by the ideals of “community care,” rather than segregation. Growing pressure for reforms in care provision (most notably, the King’s Fund Centre’s adoption in 1980 of the principles of normalization to campaign for change), culminated in the appointment of Sir Roy Griffiths (1988), who was commissioned to examine the options for the future. Griffiths’s proposals centered around the idea(1) that care should be designed to enable the people involved “to live as normal a life as possible” (Griffiths 1988, 1). This ideal was incorporated into a government white paper that laid out the policy for situating where people could receive care in the wider community, gave people a voice in the care services that they use, and stipulated that care services should be assessed on the basis of their potential to improve a person’s independence and quality of life (Department of Health 1990).

There have been criticisms of how well “community care” has met its goals (see, for example, Emerson and Hatton 1994). Walmsley (2001) argues, for instance, that the agenda for evaluation and structuring of care services has for the most part been set by the concerns of the normalization principle. Normalization aims to integrate individuals into the wider community, to enhance their abilities and self-perception, and to transform their appearances so that the individuals will be more socially accepted; in addition, normalization aims to give people valued social roles, enhanced personal competencies, and a positive social image (Wolfensberger 1983). As Walmsley points out, the various ideas that surround the normalization principle are often used as an “evaluative yardstick” with which to assess the quality of services with respect to their capacity to facilitate personal choice, dignity, the presence of “normal” relationships, and so on.

In recent years, voices have emerged that call for attention to be paid to a wider set of issues than those addressed within the terms of “normalization.” For instance, Goodley (2001) argues for a focus on how the epistemological foundations of the concept of learning difficulties promote understandings of learning difficulties as an individualized pathology and make available a whole set of diagnoses and interventions into people’s lives. In addition, Gillman, Heyman, and Swain (2000) show how diagnostic labels create particular pathologies, which are assumed to be an embodied part of individual identity, create individuals as subjects of professional intervention, and play a role in the maintenance of professional power.

The work of these authors indicates the emergence of poststructuralist—in particular, Foucauldian—arguments in literature on learning difficulties. This emerging literature re-evaluates our understanding of the category of learning difficulties itself and the care services that exist with respect to it. Allan (1996) argues, for instance, that Foucault’s conceptual framework is a useful one with which to analyze the discourses that construct special educational needs (SEN) as a specific category. Allan proposes a study of the “discontinuities and oppositions within the special education discourses” that led to the current integrationist stance; in addition, Allan recommends that in order to better understand the situation of children with SEN, we should engage in a search that aims to locate points of resistance to the “micro-physics of power” that affects these children. Consider this chapter a contribution to the endeavors that these other authors have already begun.

### *The Relevance of Foucault*



Foucault invoked a critical orientation toward the “games of truth” (Foucault 1997b) to which we relate as subjects, constitute ourselves and our systems of knowledge, and formulate problems for thought. For example, he questioned the context in which certain kinds of behavior or suffering (such as delirium or persecution) become “problematized as an illness” (Foucault 1989), as something to be cured in specific institutions, and in relation to which the individual subject is constituted according to discourses of health and illness. Furthermore, Foucault identified three domains from which to orient oneself to this sort of questioning, that is, three domains within which to engage in a critical ontology of ourselves: (1) the domain of truth through which we become constituted as subjects of specific forms of knowledge; (2) the domain of power in which we are constituted as subjects acting upon others and acted upon in particular regulated ways by others; and (3) the domain of ethics “through which we constitute ourselves as moral agents” (1997c, 262). Foucault’s work was, at different points in his career, concentrated on each of these domains.

Foucault’s historical ontology of truth, which focused on how particular objects came to take up a place in a particular system of knowledge or discourse of truth, aimed to uncover the rules by which a series of objects “are juxtaposed and placed in succession” (1972, 41) in order to form a particular field of knowledge. For Foucault, objects are not waiting, fully formed,

and exterior to discourse, for their discovery by the discipline that was destined to know them; rather, discourses “systematically form the objects of which they speak” (1972, 49).

With reference to learning difficulties, this domain of ontology leads to the realization that we are not dealing with an essential pathology whose nature resides outside of discourse, awaiting its discovery by medical or psychological knowledge. Learning difficulties is not a “condition” about which we can unproblematically amass absolute knowledge; rather, it is a discursively constituted object. The ways in which concepts of “mental abilities” are constituted, and in which they emerge as particular types of problems in certain fields of knowledge, produce what we understand as “learning difficulties.” The human subject is in turn rendered knowable as an object of these forms of knowledge.

To understand why Foucault identifies power as a domain of ontology, two points must be kept in mind. First, Foucault regards power as productive (rather than merely repressive). Second, Foucault argues that power is dynamically linked to forms of knowledge. The ways that specific forms of knowledge emerge render people knowable in relation to them. Particular aspects of people are thus created of which power can take hold. These forms of knowledge and power constitute what is desirable to be done with people, how they are to be understood, related to, organized, and so on. For example, Foucault showed how the emergence of a new object of thought relating to criminality—namely, delinquency conceived as an essence residing within the individual—related to a shift in the way that power functioned with respect to punishment. New knowledge and new forms of judgment (concerning, for example, drives, passions, maladjustments) entered into consideration; accordingly, punishment became focused upon altering criminal tendencies, on neutralizing a dangerousness within the criminal (Foucault 1979). Power, in its dynamic links with knowledge, therefore, is productive of interventions into people’s lives, of ways of relating to them, and of ways of acting upon their conduct. Power does not stand against its dialectical opposite of a sovereign, transcendental subject whose nature it represses (Foucault 1988). Rather, the subject is constituted in and through these very processes. Power categorizes individuals, marks them by their own individuality, attaches them to their own identities, imposes a law of truth that they must recognize in themselves and that others must recognize in them (Foucault 1982).

This domain of critical ontology encourages us to ask new questions about care services and environments. Rather than merely offer us a set of

criteria that can serve as a yardstick to evaluate services, Foucault's work leads us to attend to a set of interventions that act upon people and that, hence, constitute power. Foucault's concern with power makes possible the examination of judgments, decisions, imperatives, prohibitions, and relationships with others that become thinkable and livable in regard to certain people—and in which those people must recognize themselves as subject.

Foucault's (1997d) critical domain of ethics examines the modes of action that individuals exercise upon themselves. Foucault asserts that people are not merely passively positioned by forces of power and subjectification; on the contrary, people relate to themselves in an active fashion. This domain of ontology involves questioning the ways in which people constitute and recognize themselves as certain *types* of subjects, how they assign meaning and value to their conduct in line with particular ideals, and how they conduct themselves accordingly (Foucault 1987). The ideals through which self-relationships are formed and according to which one governs one's own conduct are not invented by the individual; rather, they are cultural models that offer rules, opinions, and advice on how to behave "appropriately." Through these ideals, individuals are able to question, observe, and shape their own conduct.

The ethical domain has enormous relevance for thinking about the situation of people deemed to have learning difficulties. Foucault's concern with ethics allows us to examine the ways in which people are incited to constitute themselves as beings with certain rights, responsibilities, needs, and so on. By drawing on Foucault's ethics, we can consider how people align themselves with or resist particular injunctions and prescriptions for behavior, how one's identification as a "person with learning difficulties" is coextensive with a particular "way to live," and how people relate to and interact with all of these factors. The question that must now be addressed, then, is this: how are these realizations useful in evaluating care services and proposing changes?

### *A "Foucauldian" Analysis of Care Services*



A number of possible studies of care accommodation are suggested by the ideas that have been introduced in the preceding section. As Foucault (1991a) himself points out, however, it is only by working with the people involved in specific situations that the problems that they face can be solved. McNay (1994) and Allan (1996) agree with Foucault about the

importance of studying power relations from the point of view of those who are subject to that power. I shall now take this approach in order to consider the situation of people with learning difficulties who live in care accommodation.

In order to undertake this sort of inquiry, we need a method of analyzing people's experiences of care accommodation in relation to Foucault's three domains of critical ontology. There is an important point to note here. This study should not begin by adopting a "Foucauldian method." Our aim is not to analyze the same sorts of texts, nor to attempt the same analysis in which Foucault himself was engaged. As he noted, the analyses in which he was involved were local and specific (1991a). It would be wrong, therefore, to proceed from the assumption that the findings that Foucault presented represent the characteristics of power that will exist in all situations at all times. Rather, the aim of this inquiry should be to promote a way to listen to people's accounts of their situation, a way that can use Foucault's three domains of critical ontology. This style of analysis will enable us to attend to what people say about their situation in a way that reveals how they are positioned by the actions of power and how they interact with and relate to these forces. Our aim is, thus, to formulate an idea of the particular problems with respect to power and subjectivity that certain people are made to confront.

I take the position, influenced by Foucault and discourse analysis (see, for example, Parker 1996), that what people say about their situation implicitly contains a particular picture of the social world to which they relate. Foucault treated *discourse* "sometimes as the general domain of all statements, sometimes as an individualized group of statements, and sometimes as a regulated practice that accounts for a certain number of statements" (Foucault 1972, 80). He argued, furthermore, that

[d]iscourses are not once and for all subservient to power or raised up against it, any more than silences are . . . [D]iscourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy. Discourse transmits power and produces power; it reinforces it, but it also undermines and exposes it, renders it fragile and makes it possible to thwart it. (1978, 100–101)

The methodology that I propose for my analysis draws upon Foucault's three domains of critical ontology in order to uncover the properties of

these social worlds as they relate to power and subjectivity. The aim of the analysis is to uncover evidence of the forms of knowledge by which people are objectified, the interventions that operate upon them, the judgments, decisions, and forms of authority to which they are subject, and the types of relationships with others in which they are situated. In addition, we must take account of how people interact with these issues, how they relate to themselves as particular types of beings tied to moral imperatives, how they act upon their own conduct in accordance with this moral sense, and how they might be struggling with, and resisting, the forces of power and subjectification that act upon them.

In my research, I have applied this formula in an analysis of people's accounts of their situation in residential care in order to examine the forms of power that operate in community care accommodation, how people experience this power, how they understand themselves as subjects in relation to it, and how it constitutes problems in their lives. This research has produced analyses that suggest important new issues that must be considered in order to arrive at an understanding of these circumstances.

Anne: I stand my ground. I say, "I don't like it" if I don't like it. . . .

That's it. I speak my mind. . . . It's someone's birthday at the weekend, and . . . I feel as though I want to go out and buy them something, but you cannot do that. . . . It's not your place, it's the staff's place to go out and buy things. For instance, you can't buy a cake, a birthday cake or things like that. . . . In your own home it's different; I mean, you can do as you like in your own home, but you cannot do as you like in this home. So, only as far as you can go. If you want anything, you have to ask for it. If you want to go out anywhere, you have to ask to go out. . . . In these sorts of homes you have to ask permission to do things like this.

Paul: I speak my mind. I can't help it. . . . The managers don't like you to speak your mind. It's not heard of where they're concerned. . . . You have to fight for what you believe, what you believe is right, but you're, you're just a bad boy, aren't you, because you're not being quiet.

SY: Yeah. So, you think you're supposed to be a good boy all the time, then?

Paul: You're supposed to be a good boy and be quiet, aren't you?

SY: Mmm. So, what sort of things—what's being good like? . . .

Paul: . . . You're supposed to just take what they give you, and not say no.

But I still don't do it. I won't do it, because I believe there should be a voice. We've got a voice, and we should be able to use it.

SY: When you do, do you think people listen very well?

Paul: No, they don't listen.

The first thing to notice in Anne's and Paul's accounts is the way that they talk about themselves in relation to things that they can and cannot do, and the way that they are expected to behave. By referencing these restrictions and expectations through the pronoun *you* (i.e., "you have to ask to go out," "you're supposed to be a good boy"), Anne and Paul reference not merely themselves personally, nor, clearly, anyone in general, but anyone in a particular situation—that is, anyone living in care accommodation. In effect, they recognize a specific place or subject position that they occupy that carries with it imperatives and prohibitions, and certain relationships with specific others. Their construction as members of the category of people who require care for learning difficulties thus makes particular interventions into their lives possible. Specific ways of thinking about these people are brought into being that place them in a position in which specific other people (the homes' staff) manage and supervise their lives. So, when "you" are a subject of care, "you" are supposed to be good and quiet, "you" require permission to go out, and "you" must know what "your" place is in the home.

These interview extracts illustrate one way in which the subjectification of people as members of the category of "people with learning difficulties" divides them from "normal" others and creates specific institutional interventions into their lives. It is also possible to see that the residents of care accommodation are conceptually divided from the staff who administer their homes. The definition of an individual as a subject of care accommodation carries with it a whole series of prescriptions and proscriptions on behavior that constitute a "place" that residents (as distinct from staff) occupy in these homes. This "place" puts limits on what residents can legitimately do, and delimits what staff can legitimately do to them. For instance, Anne says that it is not "your" place to buy presents for other residents, and Paul says that "you" are expected to be "good" and quiet. Other research participants spoke in a similar fashion about things that "you," as a resident of a home, can or cannot do, things that are done to or for "you," and things that "you" must accept or with which "you" must endure. Participants spoke (for example) about the need to ask permission to throw away their own rubbish or to put decorations in their rooms, that it was not thought to

be “their place” to cook their own meals, that they were answerable to others in their performance of certain chores such as cleaning or washing or in terms of their conduct and behavior. These factors, in regard to a specific “place” in the home, shape the relationships that the people who live in care accommodation have to their environment and to specific others, namely, the staff, whose role it is to supervise, observe, and manage their conduct. These relationships constitute systems of power in which the participants in my research are enmeshed.

In addition to the management and supervision of the care residents’ lives, and the constitution of their conduct as subject to judgments of “good” and “bad” behavior, the care residents’ accounts showed that they are created as punishable beings. For the observation and judgment of their conduct is linked to punishments and sanctions that can be applied. The punishments that participants relayed in their accounts included reprimands, prohibitions against leaving the home, denial of parental visits at the weekend, banishment to their rooms or to beds, the withdrawal of certain forms of care for a given period of time, and even injection with drugs. In short, the relationships of power that are evident in participants’ accounts are also characterized by a form of authority in which staff members have the power to impose sanctions upon individuals if they do not behave in certain ways.

The remarks above can be related to Foucault’s perspective on truth and power. When people are rendered knowable according to their membership in the category of people who “have learning difficulties,” institutional interventions, judgments, decisions, prohibitions, imperatives, and sanctions around their lives and their conduct are made available. Evidence from the interviews indicates how people are constituted as subjects, how they are led to observe, and to understand, themselves as *subjects of a particular kind*.

Care residents are led to recognize themselves as occupying a certain “place” or subject position in their homes. Thus, they are led to identify particular imperatives and prohibitions as legitimately acting upon them in accordance with this “place,” and to form relationships to themselves in which they understand and manage their own conduct in line with this place (that is, subject position). Anne and Paul are aware of an impetus to govern themselves and their own conduct in line with the ideals of their supervision and management in a care environment (see Foucault 1991b). They discuss their own conduct in relation to this government. Anne comments, for instance, that although she would like to buy presents for other residents, she recognizes that this is something that someone in her position



“cannot possibly do.” Similarly, Paul says that although he speaks his mind in the home, this is something that someone in his situation is not supposed to do, something that conflicts with the ways in which “you,” as a care resident, are supposed to conduct yourself.

It is significant to note the differences in the way that the two individuals orient themselves with respect to this impetus to govern their conduct in line with the ideals attached to a particular subject position. Both Anne and Paul talk about their lives in relation to forms of power that constitute them as subjects of care, position them in relationships with specific others who supervise and manage their conduct, and impose prohibitions and imperatives upon them. In addition, they both draw upon a form of ethical technology that allows them to relate to themselves as self-expressing individuals with the abilities and rights to make their opinions heard in terms of the management of their lives; that is, they both claim to “speak their mind” and stand up for themselves. There is a tension between these two positions, a tension that the two people manage in quite different ways. Anne is positive in her orientation to the care environment and relates to herself as a self-expressing subject within certain legitimate limitations constituted by her position as a care subject. While she recognizes the importance of speaking her mind, she still recognizes there are things that “you” “cannot possibly do.” Paul, on the other hand, draws upon the discourse of a self-expressing individual in explicit opposition to his situation as a care subject, explicitly contrasting the act of speaking his mind with the ideal that, in his situation, “you” are supposed to be good and quiet. These observations connect to Foucault’s third domain of critical ontology—ethics—insofar as they concern how people are led to assign meaning and value to their conduct.

This analysis of statements made by people living in care accommodation enables us to see that they are aware of forces acting upon them and of relationships in which they are invested that constitute power. As I have indicated, this power revolves around their constitution as subjects of care whose lives are supervised, managed, and disciplined by specific others and around whom a whole set of imperatives and prohibitions come into being that they recognize as acting upon their conduct. We can also see from the accounts that the way in which people are positioned as subjects of these forms of power is something that they experience as problematic, as embodying tensions in the ways that they relate to themselves and to their environment. People are not passively positioned by dynamics of power and subjectification such that they unproblematically relate to themselves as care subjects. On the contrary, they are aware of problems that they experi-

ence with these forces, they actively take up positions in relation to them, and they draw upon different forms of self-relationship in doing so.

These engagements with forms of power and subjectification are not enabling *escape* from their effects. Rather, they are an ongoing process of struggle to relate to oneself in a particular way and to have an input into how one's life is run in the face of specific power relationships. It is tempting here, in light of what we have seen above, to search out a normative basis that will allow us to decide that these forms of power are “bad” and that we must undertake a specific form of action in overcoming them. Foucault teaches us, however, that there is a danger in speaking for and above others about their situation, and in formulating programs of resistance *for* them. The problems identified in this chapter are ones that people who live in care accommodation (not academics or social workers) must solve (see Foucault 1991a). In any case, it is not possible to banish power *per se*, since it is a ubiquitous feature of human relationships.

It is possible, however, to unmask the workings of particular forms of power, to highlight their costs, and the problems that people experience in relation to them, and, therefore, to problematize their existence. I have attempted to show that an attention to what people say about their situation that is based in Foucault's three domains of critical ontology has the potential to reveal forms of power previously hidden from view and to bring to light the costs associated with them; in this case, the costs of subjection to supervision and management in care systems and the problems that this subjection poses for people with respect to how they relate to themselves, their conduct, and their environment. Judging care services merely according to some predetermined criteria for assessing “good” care misses many of the issues about these services that the people who live amid them may find problematic. In short, it is important to pay attention to an ever-present set of dangers in the ways that people experience and interact with power.

By problematizing power in the way in which I have in this chapter, new issues arise in the consideration of care situations. In evaluating and setting out ideals for care services, there are new problems with which to deal concerning individuals' experiences of power and subjectivity. This is not to say, of course, that everything about all care situations is “bad.” Indeed, as I have already suggested, it would be contentious to imagine that power functions in the same ways in every such situation. Instead, the point to make is that we must be aware that in these situations people experience potential problems with respect to power. In addition, we must recognize that the “solutions” to these problems lie not in the formulation of programs by academics on behalf of other people. The role that the researcher

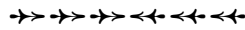
should play lies in working with people who live in care in order to bring to light the actions of power and subjectivity that they experience and, in turn, to problematize those actions. This problematization involves not changing situations *for* people; to the contrary, this problematization involves ensuring that the people who administer care no longer regard as “natural,” or unproblematic, the ways in which they operate and that the forms of power that circulate within institutions do not remain hidden or go unquestioned.

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## What Can a Foucauldian Analysis Contribute to Disability Theory?

Disability studies in the United Kingdom has begun to grow out of the narrow theoretical approach that constrained its development in the early to middle 1990s. Until the mid-1990s, historical materialism had dominated disability studies in the United Kingdom. The benefits of the materialist “social model of disability” that had governed U.K. disability studies were, for the most part, political benefits. In particular, the social model transformed the concept of disability from the prevailing medicalized conception of it that construes disability as the inevitable outcome of impairment to a conception of disability that construes it as a form of oppression (Oliver 1990).

An obvious parallel to the conceptual revolution that the social model precipitated in the United Kingdom can be found in the “second wave” feminism of the 1970s. In that historical moment, feminists began to derive significant intellectual and political capital from a sharp distinction that they drew between sex and gender, where “sex” designates a biological property of human bodies and “gender” refers to its culturally specific interpretations. By now, however, most feminists regard the sex-gender distinction as both theoretically and politically problematical.

In a world in which post-Cartesian philosophy (especially poststructuralism and phenomenology) predominates, the idea that nature and culture, or biology and society, occupy separate metaphysical spaces meets with little approval. During the 1990s, for instance, new theoretical fields that were dedicated to the study of the body, nature, time, and the emotions emerged, particularly within the discipline of sociology. Every one of these “subdisciplines” of sociology in some way rejects the validity of a sharp distinction between nature and culture.

Given this theoretical climate, disability theorists have begun to recognize that the distinction between disability and impairment is very difficult to sustain (see, for example, Hughes and Patterson 1997). Because disability theorists have begun to doubt the tenability of an absolute distinction between impairment and disability, and in their efforts to establish a theoretical agenda for the analysis of disablement, Foucault's work has become an important resource. For one thing, Foucault (as well as other post-Enlightenment thinkers) has made the body a legitimate object of social analysis (Turner 1996). As disability studies (in the United Kingdom in particular) struggles to embrace analytical frameworks that are derived from cultural studies and the sociology of the body, Foucauldian and other post-Cartesian traditions (such as phenomenology, with its accent on the embodied experiences of everyday life) have become much more attractive as sources for reflection (Hughes and Patterson 1997; Hughes 1999). To be sure, theoretical diversity and "epistemological pragmatism" are invaluable to new social movements that seek an expanded intellectual arsenal. Disability theorists ought, however, to assess the value and merit of these theoretical contributions in terms of the extent to which, and even whether, they can improve the circumstances of disabled people's lives. After all, disability studies is married (for better or for worse) to the movement for the emancipation of disabled people.

A number of critics have argued that insofar as Foucault claims that the body has no fleshy, prediscursive content, corporeality effectively disappears from his work (Shilling 1993; Lash 1991). One might wonder what such a (non)notion of corporeality could offer to support arguments that aim to show that disability oppression is embodied and lived. Indeed, I would argue that although Foucault's work can help to show that impairment is socially constructed, this is a case that could be made without that help. I suspect, furthermore, that disabled people would benefit equally, if not more, from arguments that valorize their voices, their embodied experiences, and their collective efforts to establish rights and overcome discrimination. For Foucault, these are "no-go" areas, which are located on the unproductive soil of the wilting humanist agenda that "the death of man" (Foucault 1970) has superseded. Inasmuch as Foucault declares the "death" of the meaning-giving subject, and claims that meaning is "a sort of surface effect, a shimmer, a foam" (quoted in Eribon 1991, 161), he follows the lead of Claude Lévi-Strauss and Jacques Lacan, whose structuralisms he professes to have transcended.

The claim that meaning is an effect certainly puts Foucault beyond hermeneutics. As I and a colleague have argued elsewhere, however, the

hermeneutic tradition, in general, and phenomenological sociology, in particular, can enable disability theorists to expose disability discrimination (Paterson and Hughes 1999). In another context, moreover, I suggested that an (unholy) alliance between Jean-Paul Sartre and Foucault could go some distance to advance the cause of disabled people (Hughes 1999). Although one might wish to eschew the humanist agenda that Sartre represents, it should be recognized as an agenda that is philosophically wedded to the idea of embodied agency as a matter of first principle. This cannot be said of Foucault. To the contrary, Foucault's (structuralist?) posthumanist starting point compels him to propose a "docile body" and to make a post hoc case for agency.

In this chapter, I indicate the limits of the contribution that Foucault's work can make to theories of impairment and disability, limits that can best be recognized when one examines his claims about the body and the implications of his work for questions of agency. To be sure, I allow that Foucault's work can shed light on the historically contingent set of practices that restrict the actions of humans in general and disabled people in particular. My argument, however, is that Foucault's notion of the body as a "docile" target of power underestimates that body's role as subject, that is, as an agent of self- and social transformation. Foucault argues that discourse operates independently of subjectivity. I contend, however, that because Foucault stands outside the phenomenological tradition of the body-as-subject (Crossley 2001), or the body as the material source of self and culture (Csordas 1994), he cannot theorize, nor does he appreciate, the ways in which practical sensuous activities constitute social life.

The history of impairment throughout modernity has been a history of pathologization and supervision. In the nineteenth century, disabled people were constructed as the docile population par excellence. Foucault's work can be used to illustrate the medical, administrative, and legal practices that made this so. Escape from supervision and struggle for citizenship by a self-conscious collective movement of disabled people have in addition characterized the contemporary history of impairment. In recent times, disabled people have refused to remain designated as passive recipients of charity and pity. Through various forms of embodied praxis, they have claimed the status of subjects with agency. This transition from impotence to agency cannot be easily explained by reference to Foucault's *oeuvre*. For Foucault would claim that self-empowerment is a fiction. Foucault would argue, furthermore, that the *newfound* capacity for action among disabled people is a discursive product of new reflexive technologies of power (Foucault 1980a). My argument is that although one should not reduce disability

activism to the intentions of atomic disabled actors, it is equally misguided to reduce it to the disembodied play of discourse.

### *Foucault's Fiefdom: Supervised Bodies*



The Marxist tradition that has dominated disability studies in the United Kingdom promotes a view of power that construes it as unitary, centralized, and primarily coercive (see, for example, Oliver 1990; Barnes, Mercer, and Shakespeare 1999). This is precisely the “repressive” conception of power that Foucault (1980a) regards as untenable and outmoded. For Foucault, power must be recognized as inseparable from knowledge, which is a fabrication, or production, of ocular activity (Jay 1994; Foucault 1980b). Vision (*voir*), knowledge (*savoir*), and doing (*pouvoir*) are the genealogical coordinates of power, and the “gaze” is one of its essential technologies. The gaze (a technology of power) produces information and knowledge. For example, visualizing technologies such as amniocentesis that discriminate between the normal fetus and the pathological fetus produce disabling information and knowledge *in utero* (Hughes 1999). Since information and knowledge is the (semantic) raw material that forms the basis of subjectivity, this disability discourse about the fetus produces disabled subjects in utero.

The last several claims rely upon an application to disability of Foucault's ideas about the production of knowledge and the constitution of the subject. In fact, Foucault's work is increasingly used as a “tool kit” with which to analyze the formation and productivity of specific knowledges. Without exhausting the possibilities, one could point to Nettleton's work on dentistry (1992), or texts such as Deborah Lupton (1995) and Alan Peterson and Deborah Lupton (1996) on public health, Jeff Hearn and David Morgan (1990) on masculinity, and Nikolas Rose (1989) on social psychology. Indeed, Foucault has spawned an array of Foucauldians who recognize the efficacy of his work with respect to their own specialist domains. One of the challenges of this book is to tread a similar path with respect to disability, despite the fact that Foucault never explicitly addressed disability or impairment.

What distinguishes a Foucauldian point of view on disability and impairment from the dominant materialist perspective is the powerful role that the former allocates to language and symbolism in the construction of disabled identities and disabled people as a population. From a Foucauldian perspective, disability and impairment neither refer to, nor represent, essences of particular individuals or of a certain population at large. On the contrary,



these terms refer to a de-centered subject position that is the product of the movement of power. This conception of power and its linkage to the body offers a way to explain the practices of subjectification that have variously separated, institutionalized, and normalized disabled people (Paterson and Hughes 1999; Hughes 1999). Indeed, one might argue that disability is a product of modernist biopower (Foucault 1981), that is, an effect of the medical management of people with impairments. One could conclude, in other words, that impairment itself is a product of medico-welfare discourse.

When Foucault asks how the modern clinic is born, he addresses the historical moment at which medical language—by way of the medical gaze—passes from a conflation of “seeing” and “saying” to a form of “rational discourse.” He identifies this moment with the *spatialization* and *verbalization* of the pathological, that is, “where the loquacious gaze with which the doctor observes the poisonous heart of things is born and communes with itself” (1973, xi–xii). It is only in this moment that medicine acquires the clarity and power that is necessary to make disease (and, by implication, impairment) knowable. This moment (which Foucault pinpoints historically at the end of the eighteenth century) marks the beginning of modern biomedicine and paves the way for the distinction between the normal and the pathological, a distinction that sustains disability as a form of power that both contributes to the formation of an identity and establishes impairment as its necessary and sufficient condition. In addition, this distinction establishes normality (and its opposite) as the domain around which medicine comes to be organized. Hence, the distinction sets in place the dualistic logic that legitimates the invalidation of people on the grounds of bodily difference from a medically fabricated norm and, furthermore, valorizes a regime of truth in which impairment offends against the biological laws of nature.

Because the distinction between the normal and the pathological is both implicitly and explicitly normative, the social stigma that surrounds impairment has arisen in simultaneity with that clinical distinction. As Georges Canguilhem puts it: “Every preference for a possible order is accompanied, most often implicitly, by aversion for the opposite order.” For Canguilhem, this “aversion” is not simply an act of theoretical negation. As he explains it, “that which diverges from the preferable in a given area of evaluation is not the indifferent but the repulsive or more exactly, the repulsed, the detestable” (1991, 240). With the advent of the distinction between the normal and the pathological, it becomes possible to “see” impairment and to “say” disability; in addition, disability becomes discursively constituted as

a physical or mental deficit. A group of people known as “the disabled” can only be constituted as a “real” population in the wake of medicine’s “[plunge] into the marvelous density of perception” (Foucault 1973, xiii), for in that moment, medicine reinvents itself as the rational repository of truth with respect to the biological integrity of individuals and populations. On this approach, impairments are medical fabrications that constitute disability as a “natural” subject position. From a Foucauldian perspective, that is, normalizing judgment constitutes impairment as a deficit of corporeal integrity and—simultaneously—as an invalid social position.

To be situated within a discourse of “pathology,” is to be delegitimized. Insofar as disabled people have become an object of disciplinary power, they have also become the subject matter of professional groups, whose discourses of expertise have defined and redefined that subject matter. Empirically, this position embodies a reasonable claim, for it explains the oppression of disabled people in terms of the construction of disability as a subject position that disempowering practices have fabricated. The outcome of these practices for disabled people has been the systematic closure of opportunities for agency. By the end of the nineteenth century, confinement, institutionalization, and dependency had become the reality of disabled people’s lives. Disabled people became (i.e., were inscribed as) people who could not do things for themselves, who were a burden, a group in need of intensive and intrusive systems of surveillance. When one follows Foucault’s argument about how the history of “modes of objectification . . . transform human beings into human subjects” (1983, 208), and applies that argument to impairment, one can begin to appreciate how, throughout modernity, disabled people’s lives have been blighted and demeaned by a degree of supervision that is probably without historical parallel. Pathologized by medicine, imprisoned by disciplinary power in “special” spaces, normalized by strategies of rehabilitation: this is the modern history of disability in a chilling nutshell, one that makes Foucault’s (1979) description of the great confinement, in particular, and the “carceral society” (with its techniques of power that underpin modern capitalism), in general, a powerful conceptual framework that will continue to animate debates in disability studies.

In an analysis of the United Kingdom’s Disability Living Allowance (DLA), Margrit Shildrick (1997) provides one contemporary example of the ways in which impaired bodies are produced as disabled subjects (stereotypically constructed as corporeally flawed), who become the targets of supervision. Adopting a Foucauldian approach, Shildrick examines the way in which claimants of the DLA are subjected to a questionnaire that

demands disclosure of a remarkable amount of intimate, personal information. As Shildrick notes, claimants are “obliged to take personal responsibility in turning a critical gaze upon their own bodies” (1997, 51). “No area of bodily function,” Shildrick remarks, “escapes the requirement of total visibility.” Shildrick remarks, moreover, that “the ever more detailed subdivision of the bodily behavior into a set of discontinuous functions speaks to a fetishistic fragmentation of the embodied person” (53). The deficits that the questionnaire is intended to elicit produce knowledge about the “needs” of disabled people and a “scientific” template on which to base the government of impaired bodies. For impairment (like madness) is a “product of the technologies and knowledge involved in categorization” (Marks 1999, 142). In order to show the imbrication of gender and disability, furthermore, Shildrick points out that the DLA form (in ways not unlike generic medically grounded disability discourse) assumes an ideal body that is male and normal against which the female/disabled body is measured in order to be found wanting (see also Wendell 1996).

Shildrick’s claims about the DLA, as well as other material that I refer to in this section, show that Foucault’s work on modern forms of social control is well suited to analyses of the myriad forms of surveillance and supervision that have transformed impairment into disability. If, however, the production of disabled people is based largely on the application of panoptic technologies, then it is difficult to understand the process by which disabled people have managed to establish an emancipatory movement. If disablement is a product of modern panopticism (which is a technology of power), then surely the freedom and agency required for disabled people to challenge the “eye of power” cannot exist and, therefore, impaired bodies must be conceived as docile fabrications of discourse. When Foucault argues in “The Subject and Power” (1982) that we need “to understand how we have been trapped in our own history” (210), he precludes consideration of the means by and through which some social groups spring that trap. My argument is that disabled people comprise one of the social groups that has already achieved some success in doing so.

### *Foucault’s Fleshless Passive Body*



Friedrich Nietzsche once suggested that the discourse of modernity was the “longest lie.” I assume that Nietzsche confers this distinction upon the discourse of modernity due to the impossible quest in which it engaged to discover the “truth,” as well as the implacable conviction of modernity that

its bold cogito could deliver this truth. Invisible, underrated, even despised, the carnal slipped from consideration and became a sideshow in the march of progress, as well as a shadow in the project to constitute a rational polity. The counter-Enlightenment begins with side-shows and shadows and announces the revivification of the body, desire, and the emotions, naming these hitherto disreputable characters as key players in the constitution of the social. Despite Foucault's reluctance to accept any intellectual label (and despite the traces of structuralism that can be found in his work), he belongs to this Nietzschean "poststructuralist" tradition (Lechte 1994), from which a string of concepts about the body have emerged. Indeed, the resurrection of the body is a key theme in the rise of "post-ist" thinking. As Eagleton has written, "The postmodern subject, unlike its Cartesian ancestor, is one whose body is central to its identity" (1996, 69). One must concede, however, that this very contemporary body is eucharistic, rather than incarnate; hyperreal, rather than palpable. Furthermore, this post-ist point of view situates the relationship, in contemporary social theory, between the carnal and the political, somewhere (though no place in particular) between Heaven and Earth. Thus, Chris Shilling has critiqued the Foucauldian body in this way:

[T]he bodies that appear in Foucault's work do not enjoy a prolonged visibility as corporeal entities. Bodies are produced but their own powers of production, where they have any, are limited to those invested in them by discourse. As such the body is dissolved as a causal phenomenon into the determining power of discourse and it becomes extremely difficult to conceive of the body as a material component of social action. (1993, 80)

The posthumanist subject, in its rush to flee humanism, is dispossessed of a situated carnal nature. In Lacan's posthumanist imaginary, for example, the penis (which exists) is substituted by the phallus (which does not exist). The libidinal economy is everywhere, but nowhere in particular. The body of the posthumanist subject is made up not of flesh and blood, but of bread and wine. This is a body that is devoid of material substance.

The practical (political) activity that constitutes and sustains the sensuousness and sensibility of bodily being is strikingly absent from Foucault's work. In Foucault's work, the body is a target (of power), an effect, a text upon which to write. This poststructuralist approach to the body tends to transform it into a supra-carnal substance. The body is constituted as passive, without agency, the plaything of discourse and text, and a surface ripe for inscription. One might ask: In a disincarnate world such as this would

be, how could politics be done? If, as I would argue that Foucault's position with respect to the body suggests, there is no active, creative subject, then, politics is reduced to the policing of subjects. Politics is something that is done to people, rather than something that people do. I would argue, furthermore, that such a world would be devoid of responsibility. In short, ethics and politics would be torn asunder.

To be sure, there is a "post-ist" ethico-political position in which (the celebration of somatic) "difference" is axiomatic. In theory, this position seems to suggest an advance for impaired people. On closer inspection, however, one can see that what is at stake here is vocabularies, not bodies. That is to say, the carnal is transformed into language and text. The post-ist politics of heterogeneity proposes a world of "irresistible pluralism" (Vattimo 1992, 7) and infinite tolerance, in which incommensurable vocabularies (none of which can make a claim to truth) compete in an unruly sea of shifting signification. Yet the restoration of the ethico-political seems impossible without both the restoration of the carnal and the recognition that practical sensuous activity constitutes social relations. The preceding claim may seem like an old one, but to take retreat in transubstantiated and eucharistic bodies—even in the fertile sociological pastures of simulation, symbol, text, and sign—is to concede to fatalism, if not nihilism. This problematic character of the "poststructuralist" body is reflected in Foucault's work.

As Shilling (1993) has argued, furthermore, Foucault robs the body of agency and renders it sensuously barren. For Foucault, the body does not act in and on the world; rather, the body is docile. A surface on which history is written, the body is policed into existence: it is molded by "a great many distinct regimes" (1977, 153). The body, in other words, is a product of the play of power; for power "reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives" (Foucault 1980b, 39).

There is little doubt that Foucault was more alert to the problem of agency in his later writings. Indeed, in "The Subject and Power" (1982), Foucault argues that his work can be divided into three phases, or "modes of objectification" that "transform human beings into subjects." The three modes are (1) practices of classification; (2) dividing practices; and (3) self-subjectification practices. The last of these modes corresponds to his three volumes of work on sexuality, and concerns "the way a human being turns him- or herself into a subject" (1982, 208). I would argue that with respect to the first and second modes of objectification (classification and dividing

practices), the active or creative subject is invisible; that is, the subject is a product of expert classification and regulatory techniques. When Foucault focuses on self-subjectification practices and the deployment of technologies of self (the third mode of objectification), his subject appears to acquire an element of reflexivity. In fact, Foucault and Richard Sennett argue that techniques of the self are

[t]echniques that permit individuals to affect, by their own means, a certain number of operations on their own bodies, their own souls, their own thoughts, their own conduct, and this in a manner so as to transform themselves, modify themselves and attain a certain state of perfection, happiness, purity, supernatural power. (1982, 10)

This passage might be read as a manifesto for the valorization of embodied agency. I would argue, however, that the ideas articulated in it do not represent a break from the ways in which Foucault treats the subject in his discussions of the first and second modes of objectification, namely, classification and dividing practices. The transition from surveillance, which is central to Foucault's discussion of modes of objectification in his earlier work, does not posit a creative subject; rather, the subject that is posited is one that is inscribed by power, one whose actions can be reduced to power. The Foucauldian subject, who acts by its "own means," applies techniques of the self as a reflex of domination, not as a practice of freedom.

The corrective to Foucault's approach to the body can be found in phenomenology (Crossley 1995, 1996, 2001; Williams and Bendelow 1998). Several authors have produced analyses of impairment that draw upon phenomenological philosophy (Marks 1999; Hughes and Paterson 1997; Paterson and Hughes 1999; Hughes 1999). Most analyses of impairment that draw upon the work of phenomenologists take as their starting point Maurice Merleau-Ponty's (1962) claim that the body is our point of view on the world. In the Cartesian tradition, the body is an object of perception available to the perceptive ego. By contrast, phenomenological philosophy assumes that the body is both object and subject. The body is both perceiver and perceived. Perception is a technique that is acquired through embodied practice, that is, through our very being in the world. As Nick Crossley explains it, "[T]he subject who perceives is the outcome of a habitually structured interaction between the body and environment" (2001, 79). Meaning, intention and, indeed, social relations are products of embodied human action; that is to say, these phenomena are carnally informed (Cross-

ley 1995). I contend that the “intentional experiencing body” (Marks 1999, 129) of phenomenology, a body that is made by, *and* that makes, its world, is important to disability studies and to a social theory of impairment.

Recourse to phenomenology embeds disability studies in an agentic theory of impairment in which the body is best understood in terms of embodiment, a concept that appeals simultaneously to the body as structured and active and that recognizes the body as lived (Williams and Bendelow 1998). Phenomenology, which prioritizes the body of the mundane world of sensuous experience, presupposes a creative subject who is not reduced to a “docile” outcome of the technique of modern social control. A conception of the body-subject as active opens up analysis to the world of everyday life and to the experiences of disabled people who live through, and struggle with, the oppression, exclusions, and moments of triumph that constitute that world. In short, the endeavor to produce a sociology of impairment would be greatly advanced if disability studies were to appreciate the value of a phenomenological sociology of the body. As Turner writes:

Because sociology is ultimately a social science of interaction which pays special attention to the question of the meaning of action, the sociology of the body must be grounded in some notion of embodiment in the context of social interaction and reciprocity. An adequate sociology of action would thereby start with an assumption about the embodiment of the agent and the role of this embodiment in the endless reciprocities of everyday life. (Turner 1996, 26)

Turner’s remarks suggest a place from which to begin a sociology of impairment that embraces the very hermeneutic agenda that Foucault rejects. For an analysis of impairment will best prosper on the terrain of lived experience and meaning as these emerge out of the fluidity of everyday intersubjectivity and intercorporeality. Investigation of the multiple ways in which the disabilist everyday world discriminates against impaired bodies and of how those impaired bodies “feel” about the forms of discrimination that they experience requires investigation into the carnal politics of everyday life. This sort of phenomenological and praxiological inquiry does not bode well for Foucault’s “vanishing body” (Shilling 1993, 79). Contra Foucault, however, the body (impaired or otherwise) is not simply an epistemological construct.

The body may be surrounded by and perceived through discourses, but it is irreducible to discourse. Foucauldians might argue that this is irrel-

evant as the body cannot be known apart from specific systems of knowledge. However, if we take the view that knowledge is in some sense actually grounded in and shaped by the body, rather than separate from it, then this objection appears irrelevant. (Shilling 1993, 80)

The central contradiction of the human body is this: it is, simultaneously, a potential source of our enslavement and of our freedom. Foucault would not see the body in these dialectical terms. His position is best characterized as one that represents the body as the source of our regulation and of our pleasure. Note, however, that this notion of hedonistic liberation does not even appear germane to his thinking until his later work on sexuality. In short, insofar as the Foucauldian body lacks agency, Foucault's work cannot provide a way to explain how people with impairments have transcended their discursive constitution as dependent subjects. The contrast with Jürgen Habermas (1987) is striking. As a dialectician, Habermas is interested in the play of structure and agency with respect to the ways in which people make history within the context of regimes of domination. For Foucault, the accent is on supervision and policing to the extent that the embodied subject-as-agent is deleted from the canvas of social life. As Lois McNay puts it, "Where Habermas sees the dialectic of freedom, Foucault sees the progressive subsumption of bodies under an inexorable disciplinary regime" (1994, 106).

### *Concluding Remarks*

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Nondisabled people require disabled people in order to live in the minimum security of that curious and liminal ontological space that is called "the human condition." For many people, the frailty of that condition is troublesome. For many people, impairment represents the tragedy that they hope they will never have to face. Disabilism and ageism amount to the failure to recognize and to celebrate the frailties of existence to which we are all subject. Few of us will escape life without impairment. The failure on the part of nondisabled people to recognize impairment in themselves, and to recognize this way of being-in-the-world as one of the privileges of life itself, is one of the tragedies of modern culture that needs to be bemoaned. Opportunities to transcend the myths of perfection, myths that blight the lives of disabled people, lie in the dialectic between exclusion and belonging, liberation and constraint. Foucault cannot, and would not, claim this dialectical territory. His concept of power precludes it. If, as Foucault sug-



gests, freedom is illusory, then power as agency is an absurdity. Charles Taylor (1986) has argued that it is nonsensical to invoke a concept of power that does not make reference to a concept of freedom. Taylor explains it in this way: “To speak of power, and to want to deny a place to ‘liberation’ and ‘truth’ is to speak incoherently” (1986, 93). If power is reduced to structures of domination, it is not logical for impaired people to contest disability. Only fatalism makes sense.

Until one accepts a normative point of departure that valorizes the politics of disablement and the objectives of the disabled people’s movement, disability activism is an absurd and futile exercise. As Nancy Fraser has asked, “Why ought domination be resisted? Only with the introduction of normative notions of some kind could Foucault begin to answer such questions” (1989, 29). One cannot ignore the criticisms that suggest that Foucault’s concept of power is one-sided, reduces power to domination, and, therefore, closes the door on the embodied engagement of the agent. Foucault’s debt to Nietzsche is a double-edged sword: on the one hand, this debt helps Foucault to recognize that social practices of supervision and surveillance construct the body; on the other hand, however, the debt leads him into a cul-de-sac that forecloses access to an emancipatory conception of power. Without the latter conception of power, impaired people might as well lie down to the discrimination and exclusion that disables their lives. If power is “panoptic” and ineliminable, then disability politics is inconceivable.

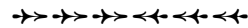
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BARRY ALLEN



## Foucault's Nominalism

It seems plausible to extend to the field of disability studies a certain nominalist point of view that is evident in Foucault's work. What I have in mind is an "implantation of impairments" thesis, modeled after what Foucault calls the "implantation of perversions." After sketching some features of this argument on implantation of impairments, I shall discuss the ideas of knowledge and power that it presupposes, then outline a critical perspective on Foucault's nominalism.

### *Implanting Impairment*



Foucault was the first (or, the most persuasive at least) to describe how, through a supposed knowledge of the "normal case," differences among people become targets of power. One example of this intermingling of power and knowledge is Foucault's description of "the perverse implantation" in the first volume of *The History of Sexuality* (1978, 36–49). The idea of perversion was one of the first ideas to surface from the medicalization of sexuality in the nineteenth century. Medicine identified a human *sexual instinct*, a natural physiological function in principle no different from other natural functions, which medicine must define and cure. Perversions were deviations or abnormalities in the operation of this sexual instinct, which was itself defined by a medical perception of normality.

As Jean Laplanche and J.-B Pontalis observe, "It is difficult to comprehend the idea of perversion otherwise than by reference to a norm. Before Freud's time the term was used, as indeed it still is, to denote 'deviations' of instinct (in the traditional sense of predetermined behavior characteristic of a particular species and comparatively invariable as regards its performance and its object)" (1973, 306–7). Thus, Richard von Krafft-Ebing, a founder of sexual psychopathology in the generation before Sigmund Freud, wrote:

“With opportunity for the natural satisfaction of the sexual instinct, every expression of it that does not correspond with the purpose of nature—i.e., propagation—must be regarded as perverse” (1965, 86).

As Foucault reads the history, the more that psychiatrists looked for sexual deviants, the more they found. Sexual perversions are not medical discoveries about human nature, but are rather artifacts implanted among us by the experts who “know.” A version of this claim has been made for so-called impairments, which, it is argued, are constructed or artifactual (Tremain 2001). The argument that impairment is implanted undercuts the assumption that impairment is a physiological condition distinct from (yet somehow underlying) disability. From the World Health Organization (1980), to Disabled Peoples’ International (1982), to the Americans with Disabilities Act (1990), an impairment is understood as an individual’s deviation from a biomedical norm (Altman 2000).

While not all of these documents concur in the precise meanings that they give to the term *disability*, the degree of uniformity between them with respect to the supposed meaning of “impairment” is striking: What a society makes of this biomedical abnormality (often called the “disability” proper) is a social construction superimposed on a given biological reality. Though the idea of distinguishing impairment and disability has its critics (Tremain 2001), it continues to find favor among scholars. As David Braddock and Susan Parish explain it: “Disability exists as it is situated with the larger social context, while impairment is a biological condition” (Braddock and Parish 2000, 11; also Oliver 1996, 22; Barnes, Mercer, and Shakespeare 1999, 2–3).

Nobody is impaired all on her own, through a naturally occurring deficit that her body bears as a biophysical property. Impairment, like perversion (and disability), is not something missing, not a lack or absence; it is something added, an unasked-for supplement contributed by disciplinary knowledge and power. It is as impossible for a person to be “impaired” without reference to a statistically constructed “normal case” as for a person to be a criminal except by reference to the law. A discourse about biomedical norms, scientific though it may be, is no more true to nature, or physically true, than a discourse about criminals. Any norm is an artifact of the discipline that measures it, and has no physical being or reality apart from that practice.

Impairment is real (as real as crimes or money), though not a naturally given abnormality, but rather an artifact of the knowledge that measures the deviation from the norm. Norms and normal cases are like statutory laws and criminals: They exist, they are real, that is, effective, but only

because people agree to take them seriously as objects of knowledge. It takes pedagogy to see some difference (which might otherwise be a matter of indifference) as a deficit, deficiency, or abnormal impairment. Impairment has no reality apart from the social mathematics of normalizing judgment. A hearing child who grows up on an island of the deaf would not notice its people's difference "from the human norm." In a world arranged to accommodate the difference, it is not an impairment (Allen 1999a).

An impairment or abnormality is no less a social construction than a credit rating or an income-tax bracket. A detectable difference becomes a disabling impairment when it is made into a target of professional intervention instead of treated informally and locally as a context of everyday life. To define deviation from norms as deficits or impairments is the first step in making the subjects of this judgment into objects of knowledge and targets of power, substituting disciplinary tutelage for political accommodation.

### *Knowledge and Power*

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I shall say more about Foucault's nominalism; first, I want to say something about his ideas on knowledge and truth. For this nominalism has to be understood as a critique of much philosophical thinking about these two concepts.

The virgule, or slash, in Foucault's neologism *power/knowledge* does not equate those two terms; rather, it divides and distinguishes power from knowledge, and then relates them to each other in a reciprocal economy. Each of these terms grows with and through the other one; they confirm each other, reproduce each other, and sustain each other's authority. Knowledge of offenders, for instance, could not exist without prisons, police, mental hospitals, and courts, whose power in turn grows with the growth of knowledge. The power to punish ensures the growth and authority of a knowledge about delinquents, which reciprocates by supplying power with sophisticated techniques and rationalizing its coercion.

Power so entrained with knowledge need not falsify or repress whatever truth may be discovered, nor must knowledge sacrifice its scientific credibility merely for a debt to coercive social power (Allen 1999b). George Orwell's worry in *Nineteen Eighty-Four* was misplaced. Power cannot make it go true that black is white, or two and two are five, but it can and does govern (modify or conduct) the circulation of statements, taking (some) control over what is taken seriously, what penetrates practical reasoning,

what *passes* for true (Allen 1993a, 1993b). This currency, this circulation in an economy of serious speech acts—*not* a metaphysical “correspondence with reality”—is decisive for our experience of truth’s value.

*Effective* truth is credibility, a statement’s capacity to penetrate people’s practical reasoning, more or less subtly governing those who receive it as an important truth. The cause of such currency in statements is in the language game, the discursive formation, a contingent economy of knowledge. There is no truth that survives the desuetude of historical discourse, no truth of sexual deviance that survives psychiatry, no truth of impairment that survives a normalizing medical perception integral to a regime of disabling differences.

No science can prescriptively define a normal or healthy life. There are no “objective facts” about which bodily conditions are vital or normal and which are healthy or sick. There are no purely physical facts about the identity of the body’s functional parts or their norms of reaction, which cannot be established apart from how people are accustomed to reacting, feeling, or being able to perform (Canguilhem 1989, 93).<sup>1</sup> And “people” are always *particular* people, that is, particular groups, with their margins and exclusions.

Impairment is supposed to be the bodily reality that is cruelly mistreated by a society that disables people who are impaired. What seems more likely, though, is that impairment is itself a product of that cruelty. An impairment is not inscribed in the biological register of nature and merely given in the body. It is an artifact *implanted in the body* by the discipline that measures deviation.

In his subtle essay (1984a) on the meaning of modernity, Foucault observes how the enhancement of technological capacities in modern societies has not always led to a corresponding enhancement of autonomy. For as individuals acquire new capacities, they often (indeed usually) also become entangled in new forms of subordination. For example, the advanced robotics and other technically powerful instruments of assembly-line construction (as in the manufacture of automobiles) make workers less, rather than more, autonomous, demanding from them skills and training that have no use except for human cogs in that expensive technical apparatus. Measured in the dollar-value of their output, these carefully disciplined workers en masse are more efficient, productive, capable; yet, as individuals, they are rendered docile, perhaps even disabled, in terms of what they can do for themselves.<sup>2</sup>

For another example of how the enhancement of technical capabilities has been paradoxically counterproductive, consider how the growth of

medical intervention over the past century or more has made *iatrogenic* (physician-induced) illness a major cause of suffering (Illich 1990; Tenner 1997). The point is not, of course, that advances in medical knowledge and technology have not helped many people. The point is that medicine is now also making a lot of people sick, in new, and sometimes intractable, ways.

Consider an example from the medicine of impairment. Many authors have written about deaf culture. Harlan Lane paints a disturbing picture of deaf children who were at one time condemned to an environment where learning was not possible because of the prohibition, sanctioned by disciplinary expertise, against manual language. Faced with the choice between permitting congenitally deaf children to live with their deafness by the enabling knowledge of manual language, or expanding professional power/knowledge at the expense of those for whom they are supposed to care, the professionals have preferred resource-intensive and (to hearing people) impressively high-tech solutions like cochlear implants, which are commercially licensed in the United States for use in children over the age of two (Lane 1992, 216–30; Allen 1999a).

The coercive normalizing of welfare regimes, and the enrollment of advanced technological knowledge and apparatus for the intensification of power, create a tutelary knowledge that disciplines and governs, rather than liberates. Foucault seems to present these developments as ones that somehow call for moral criticism; some readers of his work have wondered, however, how Foucault's work provides any reasoned basis for making such judgments (Fraser 1981; Habermas 1987; Privitera 1995).

I think the answer to this perceived lacuna can be found in Foucault's late-modern liberalism. Despite the association often made between Foucault and so-called postmodernism, he accepts that, like his contemporary audience, he belongs to a society of "modern"—meaning *liberal*—principles (Allen 1998; see also Simons 1995, 116–18). The point of politics, or the negotiation of government, is to preserve and enlarge the liberty of everyone touched by the actions of government. The examples of an "aesthetics of existence" that Foucault describes, especially in the later volumes of *The History of Sexuality* (1985, 1986; also 1988), show that a deliberately aesthetic approach to personal existence requires regions of liberty (for instance, in sexual acts), where neither law nor morality opposes the cultivation of preference and the emergence of personal style.

Whether such liberty is the privilege of the happy few (as in the antiquity that Foucault studied), or the philosophical principle of a modern democracy, an aesthetic existence, the accomplishment of personal style requires liberty and is best served by government dedicated to liberty. Inso-



far as Foucault valued the concept of aesthetic existence not as an instrument with which to describe the past, but as a possibility that might be appropriated (in however altered a form) in the present, he is and should be read as a kind of liberal in political philosophy.

If Foucault is a liberal, he is in the liberal tradition of Spinoza, Locke, Smith, and Kant—a tradition that emphasizes individuality, freedom, and the limitations of government; rather than the socialist and social-democratic tradition traced out in the line from Condorcet and Mill to Keynes, Habermas, and Rawls (Oakeshott 1993). It is not difficult, from Foucault's position, to criticize the assumption, common in liberal argument down to the present, that arbitrary domination by a sovereign power is the signal threat to modern liberty. Indeed, Foucault probably did more than anyone else to identify the ironic new configurations of power in modern societies, demonstrating the need to question much that has been done in the name of welfare, security, health, and even liberation. Rather than preserve an original individuality that flourishes prior to the heavy-handed tampering of a sovereign state, he thinks we are better advised to try to *recuperate* something of the autonomy that is lost when we subject ourselves to forms of modern political rationality, especially economic efficiency and health.

### *Nominalism*



*Nominalism* is “a fancy way of saying name-ism” (Hacking 1999, 82). The term was first used to refer to medieval professors of logic in the schools of Paris and Oxford. The most well known of these original *nominales* are William Ockham and Jean Buridan in the fourteenth century, and their notorious twelfth-century precursor, Peter Abelard. What was their infamy, that in 1473 Louis XI should have had “the books of the Nominalists” confiscated and the teaching of their ideas at Paris interdicted? The usual answer is that they taught a certain theory of “universals,” namely, that “universals,” that is, kinds, categories, general concepts, are nothing but names, and a name perhaps no more than a puff of breath. In a fresh effort to break up this received view of medieval nominalism, Calvin Normore (1988) argues that it is better seen as an argument about *truth*: truth in names, *nomina*, conventional signs, language. For these nominalists, differences of truth-value in language need not and, in many cases, do not track real differences really present in nature.

This nice technical point has far-reaching implications. It is the first critical step toward dispensing with the idea that being-true is *being-true-to*

something whose identity and existence are independent of names and their use. As Hans Blumenberg observes, “[I]t becomes possible to characterize nominalism as the system of breaches of system . . . the paradigmatic reduction of the bindingness of nature” (1983, 189). Louis XI, or those who advised him, may not have seen that far into what he, or they, condemned, yet it is the part of their thought that has survived, both in so-called social construction theses (Hacking 1999), and in the work of Foucault, who more than once describes himself as a nominalist (1991, 86; 1984b, 334; 1978, 93). His position represents a formidable stand against physicalism, or the metaphysics of inherent structure. There is no such thing as nature, not if nature is supposed to be a source of determination or identity independent of historically contingent discourse (Allen 1993b).

Foucault’s nominalism actually involves two distinct, separable claims. One is a critique of physicalism or inherent structure. Here the argument is that the world does not come articulated into categories that we must discover; instead, it is we who organize and classify, who construct “facts” and verify statements about them. Foucault takes this critique of inherent, physical, or naturally given structure further than the nominalists of old; however, this argument remains a merely negative thesis about what does not exist, namely, natural kinds or natural order. It is a further, distinct conceptual move to claim that identity or structure, like its representation, is an artifact of discourse, of a *regime of true and false*, of discursive practice.

As Foucault puts it in his treatise on the archaeology of knowledge, “What, in short, we wish to do is to dispense with ‘things’ . . . to substitute for the enigmatic treasure of ‘things’ anterior to discourse the regular formation of objects that emerge only in discourse . . . relating them to the body of rules that enables them to form as objects of a discourse and thus constitutes the conditions of their historical appearance” (1972, 47–48). This is definitely a distinct claim in addition to the first one I mentioned, that is, the merely negative thesis against the metaphysics of inherent structure. The refutation of inherent structure does not by itself establish this discourse ontology. Knowledge may be a social construction without being an exclusively (or even primarily) discursive construction (Allen 2000).

Nominalists say that structure comes from language, that is, from names and conventions of representation. Foucault adds the idea of social power, whose economy is as indispensable to knowledge and truth as the names that power causes to combine and circulate. According to the “implantation of perversions” thesis, sexual perversions are discursive constructions of the calculation of sexual norms and their being taken for seriously true-or-false matters of life and death or sickness and health. More than discourse

is enrolled in this social construction; for instance, the bodies and acts of people labeled perverse. For Foucault, however, what is “socially constructed” about sexual deviancy is its *knowledge*, and that means its “truth-value,” its currency in a discourse of serious speech acts. Thus, while the concept of power/knowledge supplements the discourse of knowledge with the effectiveness of power, it does not relieve the presumptive discursive character of knowledge. On the contrary, the effect of the concept of power/knowledge, as Foucault introduces it, is to confirm that discourse, games of true and false, are the ultimate context in which to understand knowledge.

Foucault allows no important difference between knowledge and a certain prestige or discursive value for statements. The best expression for what he calls knowledge is “prestigious discourse.” This is the real topic of his “archaeology of knowledge.” Consider the four points by which he specifies the meaning of *savoir* in a theoretical treatise dedicated to the concept of knowledge: (1) “That of which one can speak in a discursive practice”; (2) “the space in which the subject may take a position and speak of the objects with which he deals in his discourse”; (3) “the field of coordination and subordination of statements in which concepts appear, and are defined, applied, and transformed”; and (4) “the possibilities of use and appropriation offered by discourse” (1972, 182–83).

What I notice in these remarks is, first, the absence of any qualification. Foucault is not talking about *some* knowledge, or even so-called knowledge; rather, he is talking about the phenomenon of knowledge itself. He is talking about objects and concepts—any object of any concept that might express knowledge. Apart from some ambiguous remarks about what he calls subjugated knowledges (of which I have more to say below), Foucault took no opportunity here or elsewhere to qualify this formal, discursive knowledge, that is, to mark it off from other things that *fully merit* the name of knowledge too.

In addition, I notice a discursive bias. Knowledge is articulated, in discourse, in a discursive practice; it is a space of positions on objects of discourse; it defines, applies, and transforms statements, and offers possibilities of use and appropriation in discourse. Foucault evidently assumes that there is no significant body of nondiscursive knowledge, effective and powerful in ways that are *just as* important to our experience as the discursive knowledge that he arbitrarily singles out for theoretical attention.

Certainly Foucault allows that knowledge mobilizes more than discourse. In one place, he says the production of knowledge interacts with “institutions, techniques, social groups, [and] perceptual organizations” (1972, 72). Elsewhere he says that knowledge “takes shape not only in theo-

retical texts or experimental instruments, but in a whole system of practices and institutions” (1997, 7). In *Discipline and Punish* (1979), he discusses all manner of techniques and practices, including methods of torture, orphanages, military drills, factory whistles, and prison architecture. My point, though, is not that Foucault fails to take the nondiscursive into account; my point is that his idea of what it means to do so is to interpret the nondiscursive (so far as it matters to knowledge) as *prediscursive*, on its way to language, and thus subordinate to discourse. As he puts it, “The prediscursive is still discursive. . . . One remains within the dimensions of discourse” (1972, 72, 76). In short, it takes discourse, statements, truth-value, to dignify “a whole system of practices and institutions” as knowledge, making the practices *knowledge-practices*; making the institutions, *knowledge-institutions*.

Without sharing the normative concerns of traditional epistemology, Foucault, nevertheless, confirms many of its usual assumptions about knowledge—for instance, that knowledge comes in a statement or speech act, that the unit of knowledge is linguistic, logical, a *logos*, and that the most important knowledge is discursively articulated and passing-for-true. These logocentric terms have never been good for describing the actual accomplishments of knowledge; and Foucault did not improve them (Allen 1997, 2000).

### *Subjugated Knowledges*



If, as I say, Foucault conceives of knowledge as contingently prestigious discourse, it may seem puzzling that he wrote so memorably of *subjugated knowledges*, even situating his own work in an *insurrection of subjugated knowledges* (1980, 81). What is subjugated knowledge, if not knowledge without formal prestige?

Foucault mentions two sites, or sources, of subjugated knowledge. One source is the knowledge of the erudite (for instance, a scholar like Foucault). The erudite archaeologist of knowledges raises insurrection against the universal impulse of knowledge, making problems for sweeping generalizations, reconstructing inconvenient details, releasing historically subjugated contents, letting the asylum and the prison speak, for example.

People who have been disqualified and marginalized are the other source of what Foucault calls a subjugated (and potentially insurrectionary) knowledge. Foucault refers to “a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naive

knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity” (1980, 81). He calls this “popular knowledge” (*le savoir des gens*), though he stresses that it is always a particular, local knowledge (not a general “commonsense” knowledge), “a differential knowledge incapable of unanimity” (1980, 82). The examples that Foucault explicitly mentions in his text are the “knowledge” of psychiatric patients, the sick, nurses, doctors, and delinquents. He seems to see in them a marginal, excluded, subjugated knowledge, running parallel to the formal knowledge of scientific medicine, psychiatry, criminology, and so on. The nurses have a knowledge of the hospital that is excluded from the formal discourse of disciplinary nursing, and the delinquents have a knowledge of the penitentiary that is excluded from the formal discourse of penology.

Writing in 1976, Foucault states that “critical discourses of the last fifty years have in effect discovered their essential force in this association between the buried knowledges of erudition and those disqualified from the hierarchy of knowledges and sciences” (1980, 82). This is, of course, especially true of his own work. He believes his genealogical researches undermine the presumption that “inscribe[s] knowledge in the hierarchical order of power associated with science.” He writes: “A genealogy should be seen as a kind of attempt to emancipate historical knowledges from that subjugation, to render them, that is, capable of opposition and of struggle against the coercion of a theoretical, unitary, formal, and scientific discourse” (1980, 85).

The puzzle is what Foucault supposes subjugated and formal knowledge to have in common that makes them both *knowledge*. This is less puzzling for the forgotten knowledge that erudition uncovers. The curious theories Foucault describes in his histories of the asylum (1965) and the clinic (1975) *were* taken seriously, *were* serious contenders for truth in their day. Much of Foucault’s philosophical point in these histories is to contrast two economies of symbolic value, two past and present regimes of truth, obliging the present to recognize its relativity and incapacity for transcendence. This erudition defamiliarizes the present as much as it makes us familiar with a forgotten past. The point is to create distance from ourselves, to see the contingency of what may otherwise seem natural and inevitable. When one inhabits a system of thought, belief, or concepts, it appears self-evident; effective contrast to another system, equally self-evident to its contemporaries, allows one to see the unity of present knowledge as an arbitrarily enforced exclusion (Burke 2000).

What erudite archaeology uncovers *was* prestigious discourse. It is only that which allows it to be found in the archive, where it would otherwise

have left no trace. But what is it about marginalized or disqualified people that justifies the description of their experiences or statements as *knowledge*? If, for Foucault, knowledge means something more or different than place in a discursive formation, he never says what more it would be; furthermore, everything he does explicitly say confirms that, for him, knowledge amounts to currency in an economy of discourse.

It must be only in a secondary, ironical respect that an excluded or disqualified speech is “knowledge.” Foucault himself says it “owes its force only to the harshness with which it is opposed by everything surrounding it” (1980, 82). In other words, there is no reason to call it *knowledge*, except for the unsettling effect that it has on the economy of prestigious discourse. To describe an excluded or marginal discourse as “subjugated *knowledge*” is an insurrectionary tactic, not a theoretical analysis. The prestige of discursive economy remains Foucault’s principal idea of knowledge.

What the excluded “knowledge” of the disqualified and the minutiae of the erudite have in common is not that they *are knowledge* (subjugated, excluded, marginal); what they have in common is that both are useful in exposing the presumed transcendence of contemporary knowledge, revealing present certainties (e.g., about sexuality, insanity, or criminality) as essentially arbitrary discursive conventions. While Foucault vaguely suggests that knowledge might be altogether different in a different world on the other side of science as we know it, in *this* world he evidently identifies knowledge with discursive prestige.

### *Discourse and the Body*



Some disability theorists have criticized Foucault for emphasizing discourse over subjectivity and agency (Whyte 1995). Yet this criticism is most suggestively answered in Foucault’s late work on subjectivity, where he overcomes his temptation (most evident in *Discipline and Punish*) to efface freedom and subjectivity, and tries to find a balance between what power and knowledge contribute to personal experience, and what the relation that we take to ourselves as subjects contributes to that experience (1984b, 1984c).

Foucault’s approach has also been accused of denying “the sensuous materiality of the body in favor of an ‘antihumanist’ analysis of the discursive ordering of bodily regimes” (Turner 2000, 255). Yet, Foucault says that the whole point of the introductory volume of *The History of Sexuality* is “to show how deployments of power are directly connected to the body—

to bodies, functions, physiological processes, sensations, and pleasures; far from the body [being] effaced, what is needed is to make it visible through an analysis in which the biological and the historical . . . are bound together in an increasingly complex fashion in accordance with the development of the modern technologies of power that take life as their objective.” The history of sexuality will be “a ‘history of bodies’ and the manner in which what is most material and most vital in them has been invested” (1978, 151–52; also 1979, 25).

I am not making either of these familiar criticisms. My argument is not that Foucault reduces subjectivity to an objectifying discourse of knowledge. Nor would I deny his originality in showing how modern techniques of power and disciplines of knowledge invest the body at the most material, corporeal, vital level. My point is that when, as he says, “in becoming the target for new mechanisms of power, the body is offered up to new forms of knowledge” (1979, 155), this knowledge is conceived in an overwhelmingly linguistic, discursive, and indeed academic, scholastic way.

To say that norms, deviants, impairments, and so on are socially constructed is to say they are artifacts; it is not, or should not be, the claim that a specifically *discursive* practice accounts for their existence or effectiveness. Calling the objects of knowledge artifacts or constructions says something about their conditions of existence, which include us, our history and practice, but it does not follow that the primary construction or practice of knowledge is discursive. No discourse or discursive prestige enables a person to use a needle well, to dance well, or to design a good bridge. Trying to translate nondiscursive knowledge into language is largely pointless. No stretch of discourse, no discursive regime, encompasses a potter’s knowledge of clays, a clinician’s knowledge of symptoms, an engineer’s knowledge of design (Allen 1996).

A more consistent constructionism would overcome the linguistifying, discursive bias that nominalism inherits from its origin in philosophical logic. It would take up the nominalist critique of inherent structure, but would refuse the extraneous thought that the constructions of knowledge are preeminently discursive. Knowledge may well be a social construction; but what is constructed are artifacts in their infinite diversity. There is more to *Homo sapiens* than *logos*, more to knowledge than words, more to its value than an irrefutable discourse.

All history ultimately folds into evolution, where the contingency that Foucault emphasized is only more pronounced (Gould 1989, 288–90). When the temporal horizon recedes to an evolutionary perspective, then written, formal, scientific discourse takes its relatively late place in the his-

tory of knowledge, and loses the aura of preeminence with which Western thinking has invested it. Knowledge cannot be realistically inscribed in anything less than an evolving global ecology.

## NOTES

1. Our very body itself—our sensations and corporeal wellness—is increasingly *iatrogenic*—physician-generated. For a description of an iatrogenic pregnancy see Duden 1993.

2. The original motive of assembly-line production was discipline, not economic or technical efficiency. “Craft production was dismembered and subdivided so that it was no longer the province of any single individual worker. . . . New materials, techniques and machines were used in an effort to dissolve the labor process as a process conducted by the workers and reconstitute it as a process conducted by management” (Pacey 1983, 23, 20).

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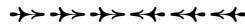
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FIONA KUMARI CAMPBELL



## Legislating Disability

### *Negative Ontologies and the Government of Legal Identities*

Sociological inquiry and legal investigation into disability<sup>1</sup> must at some point implicitly return to, and negotiate, matters of “disability” at an ontological level. I say “implicitly” because the predominant forms of socio-therapeutic analysis of disability adopt a reductionist approach, which situates “the problem” of disability at the level of attitudes or bias that lead to devaluation. Seldom is the matter of ontology—in particular, *negative* ontology—regarded as a paramount focal concern in unpacking disability subjectification. In what follows, I seek to redress this imbalance. In order to do so, I foreground the ontology question. In particular, I discuss disability-negative ontologies and the ways in which these ontologies are inflected in the practices and effects of law.

### *Ontology Wars and the “Unthinkability” of Disability*



A system of thought . . . is founded on a series of acts of partition whose ambiguity, here as elsewhere, is to open up the terrain of their transgression at the very moment when they mark off a limit. To discover the complete horizon of a society’s symbolic values, it is also necessary to map out its transgressions, its deviants.

—MARCEL DETIENNE, *Dionysos Slain*

Activists with disabilities have placed great trust in the legal system to deliver freedoms in the form of equality rights and protections against discrimination. While these equalization initiatives have provided remedies in the lives of some individuals with disabilities, their subtext of disability as

negative ontology has remained substantially unchallenged. It is crucial, however, that we persistently and continually return to the matter of disability as negative ontology, as a malignancy, that is, as the property of a body constituted by what Michael Oliver refers to as “the personal tragedy theory of disability,” a conception in whose terms disability cannot be spoken as anything other than an anathema. On the personal tragedy theory, Oliver notes, “disability is some terrible chance event which occurs at random to unfortunate individuals” (1996, 32). In the terms of the “tragedy theory,” disability is assumed to be ontologically intolerable, that is, *inherently* negative. This conception of disability underpins most of the claims of disability discrimination that are juridically sanctioned within the welfare state and is imbricated in compensatory initiatives and the compulsion toward therapeutic interventions. Insofar as this conception of disability is assumed, the presence of disability upsets the modernist craving for ontological security.

The conundrum of disability/impairment is not a mere fear of the unknown, nor an apprehensiveness toward that which is foreign or strange (the subaltern). Disability and disabled bodies are effectively positioned in the nether regions of “unthought.” For the ongoing stability of ableism,<sup>2</sup> a diffuse network of thought, depends upon the capacity of that network to “shut away,” to exteriorize, and *unthink* disability and its resemblance to the essential (ableist) human self. As Foucault explains:

The unthought (whatever name we give it) is not lodged in man [*sic*] like a shriveled up nature or a stratified history; it is in relation to man, the Other: the Other that is not only a brother but a twin, born not of man, nor in man, but beside him and at the same time, in an identical newness, in an unavoidable duality. (1994, 326)

In order for the notion of “ableness” to exist and to transmogrify into the sovereign subject of liberalism it must have a constitutive outside—that is, it must participate in a logic of supplementarity. Although we can speak in ontological terms of the history of disability as a history of that which is unthought, this figuring should not be confused with erasure that occurs due to total absence or complete exclusion. On the contrary, disability is always present (despite its seeming absence) in the ableist talk of normalcy, normalization, and humanness. Indeed, the truth claims that surround disability are dependent upon discourses of ableism for their very legitimation.

The logic of supplementarity, which is infused within modernism’s unitary subject and which produces the Other in a liminal space, deploys what

we might call a “compulsion toward terror”: a terror, ontological and actual, of “falling away” and “crossing over” into an uncertain void of disease. Such effects of terror may produce instances of disability hate crimes, disability vilification, and disability panic. The manifestations of this terror rarely enter judicial domains, but rather are excluded from law’s permissible inquiry and codification. In short, this erasure forecloses the possibility of pursuing legal remedies through the refusal of law’s power to name and countenance oppositional disability discourses. Disability “harms” and “injuries” are only deemed bona fide within a framework of scaled-down disability definitions (read: fictions) elevated to indisputable truth-claims and rendered viable in law.

Law’s collusion with biomedical discourse informs us not only about modes of disability subjectification; in addition, and more importantly, that collusion informs us about what it means to be “human” under the rein/reign of ableism.

Thus far, I have discussed (at the center, not the periphery) matters of an ontological character in order to introduce the notion of the ontological terror, that is, the *unthought* of disability, as a significant actor in the promulgation of ableism with law in liberal society. In the next section, I turn to consider *practices of freedom* as they are actualized within this ableist regime of law.

### *Chasing Freedom and Autonomy—a Recapitulation of Ableist Subjectivity?*



An able-bodied and competent person is thus a body with a set of given functions, skills and properties, which are steered by a central command unit—the consciousness—which is situated in the head. Agency, mobility, the ability to communicate verbally, to make discretionary judgments, make decisions and implement them—is thus located in the body and in the self residing in that body.

—INGUNN MOSER, *Against Normalization*

Within contemporary Western, neoliberal societies, freedom is held to be an inalienable and inherent right of the atomistic individual citizen. Indeed, the *ethos* of freedom is a foundation of the politics of our present, a mark and effect of justice and the other virtues of practiced democracy—that is, a measure of a society’s true worth, of the degree to which it is “civilized,” and the extent to which it is “advanced.” People who live in Western neoliberal democracies are seduced into freedom, the utopic dream that holds

within itself a promise, that is, the vision of an alternative way of living. For disability activists, in particular, and for many of the other folk who live on the underside of liberalism, the *ethos* of freedom has performed as a source of emancipation that contains a promise to address “social injury.” As Wendy Brown (1995, 7) reminds us, however, there is a paradox inherent to freedom: the incitement of freedom requires the very structures of oppression that freedom emerges to oppose.

In recent times, the practices of freedom have been molded and codified into the apparatus of the welfare state, citizenship, and legal personality. In the terms of this apparatus, freedom is represented as *autonomy*, where this ideal encompasses the drive toward potential maximization, which invokes the performance of a choosing, desiring, and consuming subject (cf. Foucault 1997). Furthermore, the subject of the neoliberal welfare state is assumed to be an independent center of self-consciousness, who holds autonomy to be *intrinsically* valuable. In the words of C. B. Macpherson (1964), neoliberalism’s normative citizen is a nominal “possessive individual.” The nominal individual is

free in as much as he [*sic*] is proprietor of his person and capacities. *The human essence* is freedom from dependence *on the will of others*, and *freedom is a function of possession*. . . . Society consists of relations of exchange *between proprietors*. (Macpherson 1964, 3; emphasis added)

Macpherson’s description of the neoliberal subject implies that all people must fit with a regulatory ideal; however, it is probably more correct to say that the thrust of shaping identity under neoliberalism aims for a “best fit,” that is, a normalizing, or morphed approach. The tool of comparison, the arbiter of normativity, is the “benchmark man.” As Margaret Thornton explains it, the paradigmatic incarnation of legality—the normative citizen—represents the standard against whom all others are measured and is invariably white, heterosexual, able-bodied, politically conservative, and middle class (1996, 2).

Despite Thornton’s suggestion, techniques of self are usually sought, *not* imposed, for each of us is enrolled in the task of self-appropriation and self-designation. The “free” citizen is one who can take charge of herself, that is, act as her own command center. When the citizen of neoliberal society is defined in terms of self-mastery, it may not be possible for some disabled people to be truly “free” in these contexts, unless some protectionist (i.e., paternalist) strategy or ethics of “care” is employed. In any case, the sovereign liberal subject will not be destabilized until, and unless, we refute

“autonomy” as the basis for normative legal theory and revise the meaning of “humanness” in terms of relationality. Until we accomplish these theoretical and political tasks, we will be required to manage or govern “disability” in ways that ensure its presence only minimally disrupts the truth-claims of legal discourse and its systematization.

Under liberalism, the production and government of disability is facilitated, in part, through its taming into a mere logical and discrete etiological classification and ensuing ontological space. The performative acts of a “logic of identity” reduce the disparity and difference of disabled bodies to an unity (see Foucault 1980b, 117). In law, we find this logic of identity expressed in the ideal of impartiality, which is predicated upon the benchmark legal subject. Although a great deal of feminist literature (Cheah, Fraser, and Grbich 1996; Grbich 1992; Howe 1994; O’Donovan 1997) has critiqued this allegedly impartial figuring of the legal subject, that work has not addressed the ableist underpinnings of that subject. A more thoroughgoing analysis of “legal man” would extend the reasoning of those feminist critiques to incorporate ableism as a key characteristic of rampant masculinist subjectivity. Without ableism, masculinist figurings would (we might say) “lose their balls.”

The implications of classifying practices go even deeper than this sort of critique suggests. For the unruly, monstrous, and boundary-breaching qualities of disability must be tamed in ways that distinguish that category from other fluid and leaky categories (such as illness, poverty, and ageing) with which it is associated (see Wendell 1996; Shildrick 1997). Corporeal slippages of the disability kind need containment, a civilized workability for procedural justice, a regulated liberty that produces practices of normality, rationality, and pathology. This regulated liberty is exemplified in the continued use of intelligence tests to separate the “eligible” from the “ineligible” within international and national<sup>3</sup> disability legislation (despite serious concerns about the validity of such tests).<sup>4</sup> Nevertheless, disability is not only catachrestic, but it is also contestable. Thus, I submit that matters that should be regarded as ontological in character are inextricably bound up with the politics of inclusion. Linton adds weight to this conclusion when she suggests that insofar as “the term ‘disability’ is a linchpin in a complex web of social ideals, institutional structures, and government policies,” many people have a vested interest in maintaining a tenacious hold on its current meaning, which is “consistent with the practice and policies that are central to their livelihood or their ideologies” (1998, 10).

Let us consider what the embeddedness of disability implies for understandings of that category and the ways in which disability figurings are

mediated in law. The working model of inclusion is really only successful to the extent that people with disabilities are able to “opt in” or be assimilated (normalized). This model of inclusion assumes that the people who cannot, do not, or otherwise refuse to “opt in,” will developmentally progress toward autonomy over time. Indeed, the governing of liberal unfreedom responds to the problem of what should be done with “governing the remainder,” that is, those who are identified as “less than fully autonomous” (Hindess 2000, 11). Hindess identifies three approaches that are taken to governing “the remainder.” They are (1) a clearing away;<sup>5</sup> (2) the compulsion toward disciplinary techniques (such as the normalization principle); and (3) targeting external causes by creating welfare safety nets. In order to institute these sorts of “dividing practices” (Foucault 1983, 208) of subjectivity, the aberrant subject may be extinguished (either before or after birth); be “reappraised” (for instance, fabricated as a “rehabilitated person”); become *nearly* able-bodied (via a morphed passing); or become benevolently transfigured into a “deserving” welfare recipient *supra* the economy.

Law plays an exacting and explicit role in this subjectifying activity of government. Legal intersections/interventions facilitate this subjectification by allocating and regulating populations into fixed and discrete ontological categories (such as disability, gender, sex, and race) in order that the subjects assigned to these categories can be rendered visible and calculable (Foucault 1976, especially 135–59; 1994). The fixity of disability (which is assumed to be a pre-given property of human bodies) within both legislative and case law not only establishes the boundaries of permissible inquiry; in addition, it establishes the legal fiction of “disability” in the first place. It is this reification of disability (which is based more often than not on biomedical technologies and ascriptions) that reinforces the centrality of the ableist body and the terms of *its* negotiation. The formulations of disability that disability activists often engage, and which are enshrined in disability related law, in effect discursively entrench and thus reinscribe the very oppressive ontological figurings of disability that many of us would like to escape. Alternative renderings of disability, if they are not able to “fit” such prescribed “fictions,” are barred from entry into legal and other discourses. Consider, for instance, the instructions given in a recent staff survey produced by the Equity Section of Queensland University of Technology (2000).

You should answer “yes” to question 2 only if you are a person with a disability which is likely to last, or has lasted two or more years. *Please note that if you use spectacles, contact lenses or other aids to fully correct your*



vision or hearing, you do not need to indicate that you are a person with a disability, and would answer “no.” (Emphasis added)

As we can see, defining disability in terms of what it “is” and “is not” performs an emblematic function that re-cognizes the relationships between impairment and disability and civil society. I will consider these relationships further in later sections of this chapter. For the moment, let us turn our attention to the matter of legal remedies, in general, and “social injury” claims (strategies), in particular.

### *Social Injury—A Transgressive or Recuperative Tool?*



Freedom is neither a philosophical absolute nor a tangible entity but a relational and contextual practice that takes shape in opposition to whatever is locally and ideologically conceived as *unfreedom*.

—WENDY BROWN, *States of Injury*

Feminist legal scholars have attempted to rework and engage with liberalism, that is, to move away from a focus on procedural rights that do not effect substantive change. One feminist strategy that has gained currency is mobilization of the concept of “social injury,” a theoretical device that translates once privatized injuries into collectivist raced, sexed, and disabled domains from which to make claims to social and legal remedies (Howe 1990; Brown 1995; Howe 1997; Thornton 2000). In this section, I consider the arguments that Wendy Brown and Margaret Thornton have advanced with respect to these oppositional strategies of legal engagement. In order to motivate their arguments in this context, Brown and Thornton variously draw upon Nietzsche’s concept of *ressentiment* (see Nietzsche 1969, 20, 36, and *passim*).

In the opening pages of *States of Injury: Power and Freedom in Late Modernity*, Brown asks: “What kinds of domination are enacted by practices of freedom?” (1995, 6). With respect to the social injury project, we can ask: what kinds of domination does the social injury project (as a practice of freedom) enact? The evolution of antidiscrimination law has in fact led to the codification of injury, victimhood, and dependency within an overall context of docile subject positions. An analysis of social injury involves the development of a righteous critique of power from the perspective of the injured. Such an analysis delimits a specific site of blame by constituting certain sovereign subjects (and events) as responsible for the

“injury” of social subordination that other subjects experience (Brown 1995, 27). As Brown notes, the “social injury” project establishes certain harms as “morally heinous in the law.” Exactly which “harms” does the social injury project recognize? That is, what kinds of “harm” have legitimacy before the law? I would argue that with respect to disability an uncritical approach to social injury has (at best) established certain authenticated sites and specific instances of “disability discrimination” as harm.<sup>6</sup> The discovery of these “harms” has not, however, been extended to the identification of “ableism” as their *very font*.<sup>7</sup> In short, disability discrimination is an *outcome* of the practices of ableism, not their cause.

The conditions of engagement within the emancipatory project require that “the injured” relinquish their investment in a harmed politicized identity in order to be free. But does it work that way? What kinds of ontologies of disability does the social injury project require disabled people to trade in, renegotiate, and maintain? I contend that the use of legal mechanisms to structure political demands is an act of self-subversion that enforces an internalized ableism. The political identity of disability (i.e., “the disabled citizen”) within law not only contributes to an essentialized and exteriorized ontology; in addition, it normalizes and delimits “disability” in order to make it regulative. Following Brown, we can say that the language of (disability) recognition in law “becomes the language of unfreedom,” that is, “a vehicle of subordination through individualization, normalization, and regulation, even as it strives to produce visibility and acceptance” (1995, 66). In other words, the inscription of certain figurations of legal disability requires that disabled people’s “experiences” be regulated within the confines of juridical formations, which ultimately foreclose any alternative perspectives. Furthermore, this form of procedural justice conveys the message that in order to be free within neoliberal societies, disabled people must submit to the strictures of ableist renderings of disability in law, that is, renderings of disability as a personal tragedy.

Thornton (2000) offers an optimistic reading of a politics of *ressentiment*. Although the picture of a politics of *ressentiment* that Thornton paints might at first appear attractive in its treatment of disability subjectification, she fails to adequately consider the impact of negative ontologies of disability upon the formations of disability subjectivities in law.

In a critical review of Australia’s Disability Discrimination Act of 1992 (DDA), Thornton concludes that neoliberalism and its shift from equal *opportunities* to equal *responsibilities* provides evidence that disabled people can only be assimilated (accommodated) if they replicate their benchmark *confrères* and do not make too many economic demands on the system. As

Thornton puts it: “Neo-liberalism is discomforted by prophylactic measures that are perceived as impediments to the freedom to pursue profits” (2000, 19). Indeed, the tensions that arise due to the necessity to work on the “unproductive” disabled body in order to make it “productive” in a recessionist economy grow increasingly evident.

Despite this rather disastrous situation, Thornton maintains that not all is lost because a politics of *ressentiment* allows people with disabilities to “come out” about disability discrimination and thereby enact positive images of disability. Thornton claims that the focus of *ressentiment* produces a groundswell of dissatisfaction on the part of people with disabilities, where such sentiment can be deployed as a positive force. Thornton recognizes that *ressentiment* can produce emotions (such as passivity and fear) other than righteous anger; however, she suggests that these other emotions can be attributed to, and are a consequence of, the vulnerability of a person who speaks from an institutionalized context (2000, 20).

I am not convinced by this argument. Disabled people who are confined by an institutional location are not the only ones to display emotions of antipathy, ambivalence, and fear. I would argue that *all* people with disabilities confront the daily challenges of internalized ableism when negotiating daily existence in a world that erases our value, though these challenges always vary in their degree and form.<sup>8</sup> Contra Thornton, I am inclined to propose that neoliberalism’s engagement with minority identities provokes a politics of *ressentiment* on behalf of the “majority.” We need only remind ourselves of the cries of “special rights,”<sup>9</sup> legislative rollbacks, and reactive campaigns, both in Australia and the United States. We might find that there are limits to securing equalization protections within the law and social policy, especially in a political climate where the mantras of self-reliance and mutual obligation are increasingly invoked, and complaints about “compassion exhaustion” are often articulated. Although well intentioned, the promotion of social injury strategies may easily result in unintended consequences, such as an increase in disability resentment and hate crimes.

The growing number of appeals made to disability-related antidiscrimination legislation might, as Thornton suggests, contribute to the emergence of a new way to think about citizenship, a new way in which disabled people have “the tenacity and conviction” to believe that they are justified in complaining about discrimination (2000, 22). Yet, disabled people’s complaints must be funneled into the denunciatory processes of reductionist and single-cause classifications, which are interpreted both within and outside law through a paradigm of ableism. To be sure, possibilities for

resistance to this bureaucratic machinery always exist; however, there is also the threat that a positive politics of resentment will be chipped away and unraveled by legal prescriptions of disability and foregoing remedies, which foreclose oppositional renderings of disability and play into (provoke) the internalized ableism of the complainant.

Is the concept of “social injury” (allegedly a device of social change) actually recuperative of the structures of liberalism? Or does that concept transgress those structures? As a tool of opposition, the “social injury” approach appears to offer a way out of the loop of discriminatory practices. One ought, however, to be suspicious of a practice that contributes to the elasticity and inclusiveness of the liberal polis. The enduring strength of liberalism lies in its capacity to rewrite and repair the edge of its domain and recuperate any flaws that may expose its fundamentalist and ableist basis/bias.

Thus far, I have attempted to problematize the uncritical insertion of “disability” into the neoliberalist project of freedom claims prior to an examination of the benchmark legal subject and the relationship of that subject to disability as negative ontology. In addition, I have considered the strategy of advancing complaints on the basis of claims to “social injury,” as well as the limitations of that approach given the overwhelming deployment of internalized ableism. The fact remains that disability is *not* regarded as a *neutral* category. To the contrary, it is value laden and underpinned by a theory of tragedy that makes possibilities of “pride” difficult (if not impossible) to generate.

### *Disability as Inherently Negative?*

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Deafness is increasingly an outlaw ontology, a hunted existence, an experience or way of being that, by definition, evades the biopolitics of the new eugenics. Some believe that deafness has always been an outlaw ontology, but whose fugitive status was generally ignored. How long this fugitive will keep evading the capture is increasingly in question.

—OWEN WRIGLEY, *The Politics of Deafness*

In *A Fragment on Government* (1776), utilitarian philosopher Jeremy Bentham coined the term *legal fiction* to refer to the fables and willful falsehoods committed for the purpose of “stealing legislative power, by and for hands, which could not, or durst not, openly claim it,—and, *but for the delusion thus produced*, could not exercise it” (1990, 118; emphasis added). For Bentham,

in other words, the effects of these “legal fictions” are illusions that produce a sense of debility in the very subjection of individuals, as well as the sense of trust and faith that they put in law to deliver “justice.” Thus, Bentham concludes:

[F]or the more prostrate that debility, the more flagrant the *ulterior degree of depredation and oppression*, to which they might thus be brought to submit. Of the degree of debility produced, no better measure need be given, than *the fact of men’s being* in this way made to regard falsehood, as an instrument, not only serviceable *but* necessary to justice. (1990, 18; emphasis added)

With respect to disability, it would seem that such “legal fictions” give rise to a false or distorted ontology, which is formulated on the basis of biomedical realism, and in whose terms disability is construed as a lack or negative valence. The “fiction” in this case is the suggestion that a negative ontology of disability coupled with a biomedical orientation toward disability prescriptions and evaluative rankings is necessary (i.e., a prerequisite) for the efficient administrative management and legal delimitation of “disability.” A poignant example of the continuing recitation of this kind of legal fiction of disability can be found in the introduction to a special journal issue guest-edited by Melinda Jones and Lee Ann Basser Marks (2000). According to these authors,

*Most people with disabilities would share the view that being disabled is not a desirable state to be in, and even agree that disability should, where possible, be prevented.* However, the suggestion that this carries negative implications about the entitlement to rights, or the values, respect and dignity of people with disabilities, should be resisted. While it may seem paradoxical, it is essential to meet the challenge of truly valuing those who are disabled at the same time as *taking action to prevent or limit disability.* (2000, 2; emphasis added)

The pursuit of legal liberal rights discourse that Jones and Basser Marks encourage is deployed within the context of a negative ontological framework of disability and an assumed permissibility to performatively enact injurious speech. Insofar as Jones and Basser Marks ground their arguments in this context on an a priori assumption that disability is not to be countenanced, they bear testimony to the pervasive and normalizing effects of such negative formulations as key to the maintenance of ableist ratio-

nalities; in addition, these authors reveal the recuperative and totalizing tendencies and tensions in the flawed logic of ableist liberalism (see Foucault 1980a, 98). This logic allows the rhetoric of rights to “have it both ways,” that is, to simultaneously hold out the promise of equalization and to reinscribe negative ontologies of disability that continually produce and effect subordination.

The very inclusiveness of the neoliberal conception of “citizenship” hinges upon governing disability according to an ethics of normalization and minimization. The individual of Western neoliberalism is an increasingly commodified entity. Within neoliberal societies, individuals are increasingly packaged and marketed (like inanimate objects) in terms of their respective “use-values” that become a measure of their respective worth.<sup>10</sup> Recent technological “advancements” hold out the possibilities of “elevating” the bodies (and minds) of individuals designated as disabled to the level of “nearly able.” Thus, we could argue that “enhancing” and “perfecting” technologies are really means with which to assimilate by way of *morphing ableism*.<sup>11</sup> A technological dynamic of morphing creates the illusion (that is, an *appearance*) that the “disabled” body transmogrifies into the “normal” body, effecting a corporeal recomposition and re-formation of subjectivity. Though this sort of fantastic reimaging occurs at an ontological level, the violence of some technological applications is profoundly *direct and immediate*. Robert Carver writes:

Footbinding was a method to attract a good husband and secure a happier life. At the speech and hearing clinic, I was trained to bind the mind of my daughter. Like the twisting of feet into lotus hooks, I was encouraged to force her deaf mind into a hearing shape. I must withhold recognition of her most eloquent gestures until she makes a sound, any sound. I must force her to wear hearing aids no matter how she struggles against them. The shape of a hearing mind is so much more attractive. (1990, n.p.)

In fact, an inducement to cooperate with treatments, surgery, and fittings may not be necessary due to the enduring hegemonic compulsion toward ableist normativity. Individuals with disabilities (and, in many cases, their families) develop a sense of *responsibilization*, a sense of correct ethical conduct, that is, a “regime of truth” about what it is to be a “proper” citizen. These judgments about the “correct” way in which to conduct oneself are often shaped by (or, despite) one’s awareness of the ontological, epistemological, and political effects of resistance or transgression against such pre-

scriptions (cf. Foucault 1988, 1997). In this regard, let us briefly consider a juridical move made within the U.S. context, but which could easily be replicated in the Australian context in which I am writing, namely, the introduction of the legal category of *voluntary/elective/chosen disability*.

*To “Elect Disability” or Not to “Elect” —  
That Is the Question*



Proponents of the legal concept of “elective disability” argue that legislatures should distinguish between two categories of disability when they make assessments for coverage (protection) under antidiscrimination legislation, namely, the categories of “immutable” and “elective” (or, “voluntary”) disability. As these legal theorists explain it, the category of immutable disability should apply to situations in which it is not possible (at least, not at present) to eliminate the disability (where this term usually means “impairment”). Under these circumstances, a plaintiff should be deemed innocent and, therefore, deserving. Proponents of this bifurcation of disability argue, furthermore, that the category of voluntary (“elective”) disability should, by contrast, be used in situations where disabilities were caused, continue to exist, or have been worsened due to individual “voluntary” conduct (Key 1996). Lisa Key argues, for instance, that someone who chooses not to mitigate a “condition” voluntarily chooses to be disabled, that is, makes an informed, conscious decision to live with that impairment. Key allows that this is the individual’s prerogative; she maintains, however, that “society” should not be obligated to bear the cost of that choice (1996, 84). Thus, Key proposes that coverage under the Americans with Disabilities Act 1990 (ADA) be limited by the introduction of a notion of “reasonable accommodation” according to which “unreasonableness” encompasses the choice—*refusal*—by a given individual to *eliminate* a disability (1996, 96).

Bonnie Tucker (1998) makes this sort of argument against “deaf culturalists” (to use her term) and others who oppose the correction of deafness. Writing in the context of the United States, Tucker claims that the state provides welfare and equal opportunity provision on the basis of a moral obligation. With the advent of remedial technologies, Tucker contends, deaf people (and, by extension, people with disabilities) are morally obligated to submit themselves to such technologies in order to reduce the state’s mounting financial burden. As Tucker sees it, people who are deaf

should support research endeavors whose goal is to ameliorate or eliminate deafness, rather than protest against that research. Tucker argues, furthermore, that deaf people who choose not to have their deafness (or their children's deafness) "corrected" lack (i.e., forgo) the moral right to demand that other members of society pay for the costly accommodations that are required to compensate for their lack of hearing (or their children's lack of hearing) (Tucker 1998, 10).

The claims that Key and Tucker make are dangerous. They incite a reconfiguration of disability that effectively casts bodies that are corporeally anomalous out into the wilderness where they must fend for themselves. The alternatives from which people are, in some instances, forced to choose can be grim: either submit oneself to technological procedures whose long-term consequences may be unknown,<sup>12</sup> or exist with little or no legal protection. In these instances, the very notion of "choice" seems more like wishful thinking. As Wrigley's remarks above suggest, any positive ontology of disability is an oppositional or "outlaw" ontology. What space, if any, can be made for this fugitive and dissident body? I would argue that in the world according to Key and Tucker there is no space or place for subaltern or previously unarticulated experiences of impairment/disability that diverge from the predominant biomedically defined interpretations of it.

### *The U.S. Experience: Ableism and the ADA*



The juridical power of law and its capacity to name or erase different ways of framing disability were put to the test in a series of decisions that the U.S. Supreme Court handed down in 1999. The cases that were heard related to coverage under the Americans with Disabilities Act 1990 (ADA); in particular, the cases concerned how the definition of disability ought to be delimited under the act. Under section 12102(2) of the ADA, a "lawful disability" is defined in this way:

With respect to an individual, the term "disability" means

- (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- (b) a record of such an impairment; or
- (c) being regarded as having such an impairment.



The decision rendered in *Bragdon v. Abbott*<sup>13</sup> clarified the meaning of “major life activity” insofar as it held that the phrase “life activity” should not be restricted to activities that take place in the public sphere. Furthermore, the ruling in this case extended the definition of “life activity” to include reproduction. At the time that the decision was handed down, observers believed that *Bragdon* signaled a broadening of the scope of the ADA and the range of people who could claim coverage under it. This optimism was short-lived. Against a backdrop of backlash against the ADA initiated by employer organizations and sections of the financial media, it was no surprise that a series of ADA-related judgments handed down at the end of the 1998–99 Supreme Court term redefined and re-evaluated disability in the context of mitigating<sup>14</sup> circumstances.

Known as the “mitigation trilogy,”<sup>15</sup> three cases altered the definition of disability under Title I (Employment) of the ADA. The central question in the trio of cases was whether disability should be measured in its “untreated” state, or in light of any corrective measures that would give the appearance of “normal functioning.” In the context of my discussion in this chapter, what is interesting about these cases is not only the contestability of setting parameters of disability under law; these cases are in addition interesting because they illustrate some of the ways that technological applications mediate various discourses about the ontology of disability in law. Let us turn to consider the lead case of *Sutton v. United Airlines Inc.*<sup>16</sup>

The plaintiffs in *Sutton* were twin sisters, trained as commercial pilots, who applied for positions as pilots with United Airlines in the United States. Both sisters have myopic eye impairment, with uncorrected vision less than 20/200. When these women wore “corrective” lenses, however, each of them had vision of 20/20 (or better) and were able to function similarly to individuals without a visual disability. United Airlines terminated the women’s selection interviews by arguing that the women did not meet the company’s vision requirements, which stipulate that flight personnel must have uncorrected visual acuity of 20/100 (or better). The sisters, who took legal action under the ADA, alleged that they had been denied employment on the basis of disability. Interestingly, the defendants (United Airlines) argued that the plaintiffs were *not* disabled: the women’s impairments were *corrected* through the use of technological aids; therefore, those impairments could not be said to interfere with any major life activity. Here, then, is an example of how technological engagements can destabilize the meaning of *disability*.

In its examination of the meaning of the term *disability* in the context of the ADA, the U.S. Supreme Court held that the terms could not be read to

support the proposition that determinations of whether a person is “disabled” or not should be made by evaluating an impairment in its “unmitigated state” (*Sutton* 2146–47, per O’Connor). To the contrary, the majority judgment of Justice Sandra Day O’Connor held,

If a person is taking measures to correct for, or mitigate, a physical or mental impairment, the effects of those measures—both positive and negative—must be taken into account when judging whether that person is “substantially limited” in a major life activity and thus “disabled” under the Act. (2146, per O’Connor)

What is interesting about the majority judgment is that it was based, in part, on a particular reading of the legislative history about the number of people who are reckoned to be covered under the act.<sup>17</sup> This is not the place to introduce an extended discussion of that aspect of legal reasoning. Suffice it to say that while the Court acknowledged a biomedical definition of disability, it actually erred in favor of what Jerome Bickenbach (1993) has called “an economic model of disability.” On the terms of economic models, disability is a socially constructed category that is made necessary by inescapable features of collective action and that is founded upon an individual’s incapacity to participate as a worker in the distribution mechanism (Bickenbach 1993, 93). Because the court assumed an economic model of disability, it concluded that the intention of the legislators who designed the ADA was to restrict coverage under it to individuals whose impairments are not mitigated by corrective measures (*Sutton*, 2149). This checkerboard approach to the figuring of “disability” by the court exposes the tenuous nature of legal reasoning, as well as the capacity of technological artifacts to confound and usurp seemingly self-evident formulations of “disability.”

Rather than clarifying (that is, securing) the meaning of disability, and that meaning’s relationship to the question of mitigation, the trilogy of cases (*Sutton*, *Murphy*, and *Albertson’s*) has provoked a series of new questions with respect to the technological morphing of normalcy. At stake, is the rendering of the species-typical body. The Court in all three cases concluded that individuals who “mitigate” their impairments must have this factor considered when evaluation is made with respect to their coverage under the lawful “disability” definitions of the ADA. However, none of the cases addressed the question of whether (as Key and Tucker contend) individuals have a *duty* to mitigate impairment; that is, if individuals “choose” not to engage technologies (aids, prescription drugs, and so on) that seem

to mitigate their impairments, should they still be considered disabled? For example, should a woman without arms be required to wear a prosthesis or have a hand transplant in order to be considered “disabled” under the ADA? We might extend these questions further in order to ask this question: will current (and future) morphing technologies contribute to the framing of a *benchmark mitigated disabled body*,<sup>18</sup> which is used to assess definitional conformity irrespective of the matter of usage or “choice”? Will today’s “normal” body be superseded, that is, become tomorrow’s “abnormal” body?

The ableist leanings of the law (in this instance, exemplified in rulings by the U.S. Supreme Court) are exposed in its attempts to reframe disability subjectification. Yet, such attempts at reinscription potentially enact two rather strange paradoxes: proponents of the concept of “elective disability” would prevent individuals who have rejected the normative path from accessing welfare and social security programs; yet, people who are considered (under *Sutton*) to have “mitigated” their disability may not be covered under the ADA. In other words, we are left with a rather ambiguous possibility: namely, technologies that hold out the promise to eradicate or compensate disabled bodies may, by default, create new sites of ontological and corporeal confusion. Nevertheless, the underlying subtext of law, which figures disability as anathema, remains unchallenged. One ought to wonder, therefore, how far the courts will proceed in deploying the concept of mitigation. In particular, how much compliance will the courts expect in cases where the “cure” could be more detrimental (riskier, more expensive, and so on) than the effects of the impairment? To take one example, how cognizant of the high financial costs often associated with normalizing treatments (such as immunosuppressant drugs) will legal reasoning be? Obviously the answers to these questions lie within the realm of the future; however, I suggest that it is critical to watch the reasoning used in the lower courts post-*Sutton*. My guess is that the definition of “disability” in the ADA, rather than becoming more certain and strictly interpreted, will, at the lower court level, the level of state and regional practices, produce incongruous, discordant, and fluid readings of disability.

### *Postscript on the Court*

The U.S. Supreme Court decision of January 8, 2002, in *Toyota Motor Manufacturing Inc. v. Williams*<sup>19</sup> appears to signal a narrowing of the definition of disability under the ADA. While there is no room here for a thoroughgoing analysis of the case, I want to highlight some initial observa-

tions relevant to the argument presented in this chapter. One of the key debates in *Toyota* was the relationship between impairment and disability, that is, what elements need to be present for an impairment to be constituted as disability. The strict medicalization of disability, where medicalization equals disability would seem to have been rejected by the Court—linking the designation of disability status with the effect that the impairment has on the daily life of an individual. Mention was also made in the judgment of the need to assess disability status on a case-by-case basis. The court held that in order to be included within the ambit of the ADA, “[A]n individual must have an impairment that prevents or *severely* restricts the individual from doing *activities that are of central importance* to most people’s daily lives. The impairment’s impact must also be permanent or long-term” (*Toyota III*, paragraph 5, per O’Connor). In the terms of this definition, disability is no longer governed according to a separation of domains (i.e., the public [work] and private spheres); rather, the chief elements of the definition cross domains and focus on those activities that are significant in *most* people’s daily affairs. What this means for niche activities not practiced or considered to be important by a majority of the population will remain to be seen.

Ontological themes also feature strongly in *Toyota*. Not only do these themes relate to the scaling and delineation of disability (mild, moderate, severe), but also to that carefully guarded constitutional divide between “able-bodiedness” and “disability.” The question for legal interpretation that arose from the case was how should respondent Ella Williams’s carpal tunnel syndrome be inscribed under the ADA? Again, we return to that age-old problem of shifting the goalposts vis-à-vis the normative body. For to limit “disability” under the ADA to significant or severe impairment ensures that this population stands out and is delineated from the general American population—that is, people with disabilities as a minority group. By including so-called minor impairments, however, the danger is that disability becomes a normative and not unusual experience for the general population. I believe that ableist norms of legal reasoning cannot allow for this possibility, that is, for this ontological crisis about the “normal” and “pathological” to unravel. To extricate itself from such an awkward moment, the Court in the opinion of Justice Sandra Day O’Connor (*Toyota III*, paragraph 4, per O’Connor) returned to the intentions that Congress held when it framed the ADA, arguing that if Congress intended for everyone with a physical impairment that precluded the performance of all sorts of manual tasks to be considered “disabled,” then, the number of projected disabled Americans would have been estimated at a higher

level! In *Toyota*, there is a marriage between regimes of countability and calculation and the activity of governing disability by fixing discrete ontological categories of disability in law.

*Conclusion: Putting Ontological Matters on the Agenda*



In this chapter, I have focused on the relationships between ontology, disability, and ableism by highlighting the role that law plays in reasserting an ableist dynamic. I have pointed out how under technologies of *responsibilization*, in tandem with the “gentle hand” of the ableist body of the law, the “problem” of disability resurfaces in ways that could potentially roll back the civil rights gains of the 1980s and 1990s, especially in the arena of legislative reform. I believe that an increased emphasis on coercive strategies to normalize, which are facilitated through the use of legal regimes of penalty that aim to eliminate or morph “disability,” provides persuasive evidence that neoliberal societies are sliding into a “positive,” laissez-faire form of eugenics,<sup>20</sup> albeit under the guise of the liberal promise of “choice” and “freedom.” Indeed, the very inscribing of “legal” disability may well become the new battleground of a future disability politics. My aim has been to draw connections between the notion of *disability as unthinkable* and a *logic of supplementarity* that shores up a place for an autonomous, “perfectible,” transcendent self and the necessity of preserving that constitutional divide between “ableness” (positive ontologies) and “disability” (aberrancy/negative ontologies). Legal fictions of “disability” act as an incited citation of the logic/neutrality of “ableness” within the practices of neoliberalist freedom and simultaneously promote the illusion of inclusion.

Finally, I suggest that the law’s continual reiteration of “defective corporeality,” through the designation of the legal categories “disability” and “disabled person,” disallows the “disabled” subject any escape from the normalizing practices of compensation and mitigation. This reiteration continues to negate possibilities of imagining the desiring “disabled subject” in ways that are alternatives to the hegemonic ableist figuring of the disabled body. Engagements with law reform that are based on the notion of disability as *inherently* negative will continue to produce fabricated equality rights and responses of *ressentiment*. As long as the figuring of disability as negative ontology lurks as an undercurrent of legal and welfare-economics debates—framed as part of a “cold” (ontological) *war*, that is, the *unthought* of being fully human—we have much about which to be concerned.

## NOTES

1. As a signifier, *disability* may be understood in terms of *catachresis*. That is, there is no literal referent for this concept. As soon as we discursively interrogate “disability,” its meaning loses fixity, generality, and ultimately collapses. From this perspective, I argue that the citation “disability” invokes a reading of corporeal differences, particularities, and unintelligibilities within the context of culturally delineated normative and ableist (benchmark) bodies.

2. I define “ableism” as a network of beliefs, processes, and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, as the species-typical, and, therefore, as essential and fully human.

3. For instance, Section 8(1)(b) of the Intellectually Disabled Persons’ Services Act of 1986 (Victoria, Australia) states that an assessment of eligibility be performed by use of “one or more standardized measurements of intelligence.”

4. In an early text, Scheerenberger (1983) points to some of the difficulties that arise when IQ tests are used to institute distinctions between “mild degrees of mental retardation [*sic*] and normality.” Due to the shifting of mental-age goalposts, 50 percent of the white population in the United States has been rendered “intellectually disabled.” Scheerenberger writes that “even the most ardent advocates of mental tests did not want the percentage of mentally retarded persons to deviate significantly from approximately two or three per cent of the general population” (21).

5. See Campbell 2000a, 2000b.

6. These findings should not, however, be easily dismissed and are useful for various activist campaigns.

7. For instance, there has been a hesitance amongst policymakers and law reform advocates in Australia to recognize the legitimacy of disability vilification and hate crimes.

8. Robert Mullaly (1997) points out that assimilationist incitement not only means internalized devaluation, but that the very act of participation means individuals accept an identity other than their own and are reminded by others, and by themselves of their respective (real) masked identity.

9. In Australia, there are debates motivated by the political Right according to which targeted programs and “land rights” protections for indigenous communities constitute “special rights” and thus are discriminatory toward the majority (read: white, Anglo-Australian) of the population. Similarly, when gay men and lesbians in various jurisdiction have lobbied for legislative protections in employment or property law, the Right argues that “special rights” are being claimed (consider, for example, Ballot Measure 9, Oregon, United States).

10. The move toward “mutual obligation” as a key criteria for receiving welfare is such an example. See McClure 2000.

11. The dynamic of morphing creates the illusion (appearance) of the disabled body transmogrifying into the “normal” body that results in a bodily recomposition and re-formation of subjectivity. This transmogrification usually occurs through the engagement of technological practices that mimic what is understood to be “able-bodied” or “normalcy.” The morphing aspect refers to those elements of technological

practice or application that give the appearance of bodily wholeness. For instance, amputee equals lack; returned to able-bodied status equals normal by way of prosthesis, reconstructive surgery, and so on.

12. The case of Clint Hallam, who recently underwent a radical limb transplant highlights the violence of the quest for normalcy (see Campbell 2004). According to one commentator, “Hallam was previously a well man [with amputation] and now, under the influence of immuno suppressive drugs [which are needed to keep the “new” limb viable] is a sick man” (Ferrari 1998, 17). Equally, the installation of a cochlear implant is invasive, requiring regular adjustment, often obliterating any residual hearing the recipient might have through permanent ear damage. See Wrigley 1996.

13. *Bragdon v. Abbott*, 524 U.S. 624 (1998); 118 S.Ct. 2196; 141 L.Ed. 2d 540.

14. Space precludes me from teasing out the notion of *mitigation*. However, I want to draw attention to its relational and comparative quality. One definition of the term cited in the fifth edition of *The New Shorter Oxford English Dictionary* is to “make milder in manner or attitude, make less hostile or mollify.”

15. *Sutton v. United Airlines Inc.*, 527 U.S. 471 (1999); 119 S.Ct. 2139; *Murphy v. United Parcel Service*, 527 U.S. 516 (1999); 119 S.Ct. 2133; *Albertson’s Inc. v. Kirkingburg*, 527 U.S. 555 (1999); 119 S.Ct. 2162.

16. The other two cases ostensibly followed the reasoning in *Sutton*.

17. The science of counting “cripples” throws into relief battle over the delineation of “disability” in an environment where people are turned first into objects and then into numbers. For administrative purposes, it is imperative that the (real) disabled person is made visible through the processes of calculation and therefore can be made governable. The obsession with “disability fraud” induces such questions as “who is the genuine disabled person and how many of them are there?” See Hacking 1982, 1991.

18. One of the problems of operating within the duality of “abled” and “disabled” is that the boundaries between these two signifies interpenetrate. The rise of new perfecting technologies not only reinscribe “disability”; in addition, the ascendancy of these technologies reinscribes “normalcy” (construed as that which is species-typical).

19. No. 00–1089, U.S. Supreme Court (January 8, 2002).

20. In the terms of this kind of eugenics, “market forces” shape predictable outcomes under the guise of consumerism and choice. Instead of the “old-fashioned” *negative* eugenics of elimination of the “unfit,” a “positive” approach to eugenics focuses upon the compulsion toward favored human characteristics that I term “ableist normativity.” See Campbell 2000a, 2000b.

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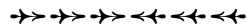
## II



## *Histories*



LICIA CARLSON



## Docile Bodies, Docile Minds

### *Foucauldian Reflections on Mental Retardation*

Traditionally, philosophical discourse about mental retardation has focused on moral issues surrounding the “mentally retarded,” including definitions of personhood, the problem of marginal cases, and what constitutes justice for people who are labeled mentally retarded. In addition, discussions of “the mentally retarded” appear in bioethical debates concerning sterilization, informed consent, access to health care, prenatal genetic testing and screening, and selective abortion (to name a few). While these issues are politically and philosophically important, philosophers have been relatively silent concerning the history and status of mental retardation as a classification.<sup>1</sup> Indeed, most contemporary philosophical discourse presumes the self-evidence of the tremendously problematic and complex category that bears the name “mental retardation.”

In this chapter, I offer a critical philosophical analysis of this category. Insofar as Foucault’s work problematizes what is taken to be self-evident with respect to institutions, power, and certain classifications of individuals, his work is historically, conceptually, and methodologically relevant to a critical analysis of the classification of mental retardation, and provides the occasion for a philosophical reorientation toward that category. Foucault explained his task in *Discipline and Punish* (1979) as an attempt to show how our modern penal system came to be seen as “altogether natural, self-evident, and indispensable.” As he put it, “It’s a matter of shaking this false self-evidence, of demonstrating its precariousness, of making visible not its arbitrariness but its complex interconnection with a multiplicity of historical processes” (2000, 225). I maintain that taking a Foucauldian approach to the historical development of this category allows the *contingent* nature of mental retardation to emerge. One of the purposes of this chapter, then, is

to challenge the self-evident nature of mental retardation *as a particular kind of problem* to be solved.

Both the history of mental retardation and the configuration of current bioethical debates (for example, debates about the execution of people labeled mentally retarded and the genetic “revolution”) reveal that the category of “mental retardation” is situated at the intersection of medical, criminal, and psychiatric discourses, which are the central themes in three of Foucault’s historical texts: *Madness and Civilization* (1988), *The Birth of the Clinic: An Archaeology of Medical Perception* (1994), and *Discipline and Punish: The Birth of the Modern Prison* (1979). Foucault’s *Madness and Civilization* is in many ways the most closely related to the history of mental retardation, insofar as there are explicit overlaps in the definitions and histories of madness and idiocy. In addition to the historical richness of this text, its discussions of the tyranny of reason and the silencing of unreason are important in analyzing the emergence of mental retardation as a classification. In *The Birth of the Clinic*, Foucault traces the development of the clinic as an organizing principle in the production of medical knowledge and the relationship of the medical gaze to the visible and invisible. These analyses can provide a conceptual framework within which to explore two significant epistemological shifts in the history of mental retardation in the United States: (1) the birth of institutions for the “feble-minded” that appear in the mid–nineteenth century; and (2) the advent of IQ testing in the early twentieth century. In addition, Foucault’s analysis of disciplinary power in *Discipline and Punish* can illuminate the power relations at work in the institutions for the “feble-minded.” Furthermore, his insights into the paradoxical rhetoric of prison reform can help to demonstrate that the history of mental retardation does not obey a straightforward pattern of development and reform; rather, definitions and practices with respect to mental retardation were sites of contestation from their inception.

While these historical texts serve as a backdrop for the reflections that follow, there are also methodological and epistemological features of Foucault’s work with which this analysis is actively engaged. In particular, the attempt to unmask the self-evident nature of practices and categories, the analysis of contradictions and oppositions within an archaeological approach to the history of classifications, and the promise of genealogy as a means of philosophical critique and political change are the three dimensions of Foucault’s work that will inform my historical investigations of the history of mental retardation. Though numerous extensive histories of mental retardation exist, I maintain that turning a Foucauldian gaze onto

the intricacies of this classification is instructive for philosophers and disability theorists who are interested in contemporary disputes regarding the “cognitively disabled.”

Foucault’s historical texts can be read as challenges to a conception of history as a linear and continuous process. In each of the aforementioned historical texts, Foucault brings to light “discursive formations” related to madness, criminality, and medical perception. As we shall see, multiple institutions, practices, and discourses constituted mental retardation as an object of knowledge. Thus, the category of mental retardation resists a simple, univocal formulation; indeed, the story of its emergence is rife with contradictions and tensions *internal* to the classification itself. In this respect, Foucault’s archaeological approach to history is instructive. In *The Archaeology of Knowledge* (1972), Foucault writes: “A discursive formation is not . . . an ideal, continuous smooth text that runs beneath a multiplicity of contradictions, and resolves them in the calm unity of coherent thought. . . . It is rather a space of multiple dissensions; a set of different oppositions whose levels and roles must be described” (1972, 155).

In what follows, I will show how this kind of oppositional analysis, when applied to the history of mental retardation, can reveal the multiple tensions and mechanisms through which the highly problematic and contested category of mental retardation has survived for more than a century. It may be argued that the many histories of mental retardation that have already been written suffice to illustrate its complexity.<sup>2</sup> However, the contribution that a Foucauldian analysis will make to this work is to provide a way in which to reconsider the *success and persistence* of this category in light of the many contradictions within it. For rather than undermining the epistemological authority and practical force of this classification, these internal tensions, I suggest, increased *the tenacity* of mental retardation as a category of “human kinds” (see Hacking 2002). Given the increasing (rather than decreasing) complexity of this category in light of the genetic revolution, the disability rights movement, and developments and challenges from numerous disciplines, the tenacious character of mental retardation as a classification has contemporary relevance, and therefore requires closer scrutiny.

Foucault’s concept of genealogy as a means by which “subjugated knowledges” can come to light is an important counterpart to the critical examination of discourses about mental retardation that come “from above” (i.e., institutional discourses, philosophical theories, “expert” knowledge produced *about* rather than *by* persons labeled as “mentally retarded”). While I will touch briefly upon certain genealogical questions

in my conclusion, the majority of this chapter will be devoted to an archaeological analysis of the history of mental retardation.

*Oppositional Analysis: A Space of  
Multiple Dissensions*



In a late interview, Foucault remarked:

To one set of difficulties, several responses can be made. And most of the time different responses actually are proposed. But what has to be understood is what makes them simultaneously possible: it is the point in which their simultaneity is rooted; it is the soil that can nourish them in all their diversity and sometimes in spite of their contradictions. (1997a, 118)

This Foucauldian insight can serve as the starting point from which to consider three conceptual pairs that have persisted throughout the history of mental retardation: the qualitative/quantitative; the static/dynamic; and the visible/invisible. There are certain points in this history when one side of these conceptual pairs was given priority in explaining mental retardation, though the other side of the pair was nevertheless present. At other points in time, both elements of the pairs were considered equally important. Although it is tempting to look for resolutions of these apparent dichotomies, the persistence of both sides of these oppositions in the history of mental retardation does not permit this. Many of the “reforms” in this history have occurred when these tensions were apparently resolved. As one examines the complex interplay of these oppositions, however, it becomes evident that these are temporary resolutions, momentary eclipses of one term by the other. These continuous features of this category can be viewed in the context of two decisive moments in the history of mental retardation that constituted radical shifts with respect to what could be said about “feeble-mindedness”: (1) the creation of institutions for the feeble-minded; and (2) IQ tests.

Foucault explains that the birth of the medical clinic in the nineteenth century prompted a “reorganization in depth, not only in medical discourse, but of the very possibility of a discourse about disease” (1994, xix). This is equally true of the new institutions developed in the second half of the nineteenth century specifically for the “feeble-minded.” These institutions were significant insofar as, for the first time, causes, definitions,

descriptions, and treatments of idiocy were being discussed and practiced within an organized institutional structure.

Though idiocy was recognized as a condition before the nineteenth century, there were no institutions specifically for people who were defined as “idiots.” In the first half of the nineteenth century, however, a process of differentiation took place in which idiocy was recognized as a distinct condition, worthy of separate consideration.

The proliferation of these institutions for the “feeble-minded” gave rise to a new professional organization, and provided the opportunity for new forms of knowledge to emerge regarding idiocy and feeble-mindedness. In 1876, a meeting was called of the superintendents of the existing institutions for the feeble-minded. This resulted in the creation of the Association of Medical Officers of American Institutions of Idiotic and Feeble-minded Person, the first professional organization devoted to the study and treatment of mental deficiency. The association’s constitution states that it aims to devote itself to “all questions relating to the causes, conditions, and statistics of idiocy, and to the management, training and education of idiots and feeble-minded persons; it will also lend its influence to the establishment and fostering of institutions for this purpose” (Sloan and Stevens 1976, 1–2). This statement reflects the many purposes of the institutions that had already been put in place, and which continued to thrive thanks to the efforts of their superintendents. By combining the pedagogical, the medical (almost all superintendents of the institutions were doctors), and the therapeutic, the institutions became the organizing principle of knowledge about feeble-mindedness amid an array of definitions, theories, categories, and proposed treatments.

The birth of the institutions for the “feeble-minded” changed the scope and limits of what could be said about idiocy. Just as the medical clinic provided “a new outline of the perceptible and storable” (Foucault 1994, xviii), the institution was the vehicle through which expert medical knowledge about feeble-mindedness could be generated. In the early twentieth century, another equally significant method of gathering and organizing knowledge about feeble-mindedness emerged: namely, mental testing (see Trent 1994, 155–68; also see Gould 1981, chaps. 5 and 6). Foucault’s histories have showed that new means of producing knowledge produce distinctly new kinds of individuals. His claim in *Discipline and Punish* that “the penitentiary technique and the delinquent are in a sense twin brothers” (1979, 255) holds equally true for the implementation of IQ testing. As we shall see later in this chapter, the advent of mental testing in the United States was simultaneous with a new “type” of feeble-mindedness: the moron. The



emergence of this new *kind* of individual had effects on the very definitions and practices associated with feeble-mindedness.

The significance of these two moments of discontinuity in the history of mental retardation—institutions and IQ testing—cannot be underestimated. I shall, therefore, examine the three conceptual pairs (which can each be viewed as a substratum of continuity amid radical epistemological shifts) in the context of these two distinct modes of producing knowledge about the “feeble-minded.”

### *Quantitative and Qualitative Definitions*

In *The Normal and the Pathological* (1989), Georges Canguilhem describes a historical shift from a qualitative to a quantitative conception of disease. He claims that prior to the nineteenth century disease was understood as ontological (separate entity to be cured) or dynamic (disruption of the general equilibrium of human beings). Both accounts, he argues, presented normal and pathological states as heterogeneous. In the nineteenth century, however, disease came to be understood in quantitative, rather than qualitative, terms: “[P]athological phenomena found in living organisms are nothing more than quantitative variations, lesser or greater according to corresponding physiological phenomena” (Canguilhem 1989, 41–42).

The influence of this new conception of disease is evident in the way idiocy was defined by many nineteenth-century doctors. Edouard Seguin’s *Idiocy, and Its Treatment by the Physiological Method* (1910) is a testimony to the rise of physiology and the focus on function, rather than anatomical structure.<sup>3</sup> Seguin, a French doctor who devoted much of his career to the study of idiocy, had a profound influence on the American institutions and classifications of feeble-mindedness. After his experiences with a class of “idiots” at Bicêtre, he was convinced that idiocy was not incurable, as many before him had asserted, and believed that “most idiots and children proximate to them, may be relieved in a more or less complete measure of their disabilities by the physiological method of education” (Seguin 1910, 5).

The belief in the curability, or at least improvability of “most idiots,” is grounded in a conception of idiocy as a quantitative, not a qualitative difference: a question of *degree* or *intensity*, not *kind*. “Idiots” were considered to be human beings “like the rest of us”; the “idiot” was simply at a lower level of development (be it physical, intellectual, or moral). In Seguin’s words, “He is one of us in mankind, but shut up in an imperfect envelope” (1910, 48). This quantitative view of idiocy was embodied in the eventual use of mental tests to classify levels of “feeble-mindedness” as various

degrees of intelligence, a method that continues to define mental retardation today.

Alongside this quantitative picture, however, we find the depiction of “idiots” as *qualitatively* different, that is, as a separate kind. “Idiots” are viewed as animal-like, subhuman, or of a different race altogether.<sup>4</sup> Generally, the most severe cases of idiocy were used to illustrate these qualitative differences. They were often described as human only in form, empty shells of humanity. Exclaiming his dismay at the discovery of idiocy in his homeland, one American superintendent of an institution for the feeble-minded writes: “But alas! . . . [One] finds, even in our fair commonwealth, breathing masses of flesh, fashioned in the shape of men, but shorn of all other human attributes. . . . Idiots of the lowest class are mere organisms, masses of flesh and bone in human shape” (Howe 1976, 37). Even the outward shape or form could be inhuman and betray signs of animality. Howe speaks of the “peculiar look so common with idiots, and which may be better expressed by the word *monkeyish* than any other.” In some extreme cases, the individual was regarded as below members of the animal kingdom: “Very few cases (we were inclined to think none could) can be found in which a being in human shape is so much below even insects, and so little above a sensitive plant” (Howe 1976, 38–39).

The association between mental retardation and animality (idiots as qualitatively different) has been drawn by philosophers in a number of ways, both in arguments that address the moral status of the “mentally retarded,” and in arguments (such as Peter Singer’s [1995] objections to speciesism) that are meant to bolster the moral status of nonhuman animals (see Carlson 1998). While space does not permit additional examples here, suffice it for me to say that titles such as that of Jeffrie Murphy’s 1984 article “Do the Mentally Retarded Have a Right Not to Be Eaten?” are a testimony to the entrenched legacy of a portrait of mental retardation that views these individuals as qualitatively different from “normal” human beings, and defines them by their proximity to nonhuman animals.

Though qualitative and quantitative portrayals of feeble-mindedness coexisted and continue to flourish, they reflect two opposing views of the nature of mental retardation. On the quantitative picture, conditions like idiocy, imbecility, feeble-mindedness were defined according to a hierarchical ordering of certain human abilities. As the IQ test became popularized, definitions depended entirely upon a numerical score, which was thought to represent intelligence. Though the relevant characteristics of feeble-mindedness changed depending on the theorist and the historical period, the underlying assumption was that “idiots” and the “feeble-minded” still fell

somewhere along the human continuum. At the same time, however, the image of idiocy and feeble-mindedness as animalistic, non- or subhuman, and racial, was equally powerful. The conviction that “idiots” were qualitatively different from other humans shaped descriptions of bodies and character, as well as technical and “scientific” definitions. This historical tension between qualitative and quantitative portraits is captured in the words of Dr. Isaac Kerlin. In describing two of his students at the Pennsylvania Training School, he writes: “Two children have attached themselves to all of us, on account of their infancy and beauty, and are justly entitled to the appellation of ‘pets’ in our household” (1976a, 285).

*Static and Dynamic Definitions in Productive and  
Protective Institutions*

Foucault explains that the institutional history of madness had begun in the creation of the Hôpital General in the seventeenth century, predating the birth of the insane asylum (Foucault 1988). Though idiocy was recognized as a condition long before the nineteenth century, there were no institutions specifically for people who were defined as “idiots.” Philip Ferguson points out that “the institutionalization of mentally retarded people in America began with the almshouses of the 1850’s and 1860’s” (1994, 24). In the first half of the nineteenth century, however, a process of differentiation took place in which idiocy was recognized as a distinct condition, worthy of separate consideration. In the United States, a legislative campaign got under way to separate “idiots” from other social outcasts, both physically and conceptually. In 1840, “idiots” and “the insane” were counted by census for the first time. Reformists like Dorothea Dix exposed the abominable conditions in which “idiots” and “the insane” were living, and argued that they had been wrongfully grouped with paupers and criminals (1976, 3–30). This campaign resulted in the creation of institutions (usually named “schools”) that were specifically for the “feeble-minded.” In 1848, Samuel Gridley Howe opened an experimental school for “idiots” (eventually named the Massachusetts School for Idiotic and Feeble-minded Youth) in south Boston. By 1888, there were institutions in numerous states, with a total of four thousand residents (Rosen, Clark, and Kivitz 1975, xviii).

Within the walls of the institutions—called “schools,” “life-schools,” “asylums”—we find two conceptions of feeble-mindedness: static and dynamic. For individuals who were thought to be impervious to education or improvement (static cases), the institution was claimed to provide shelter and supervision; furthermore, the institution was claimed to transform

into productive members of society the “cases” that were considered educable and potentially curable (dynamic cases). The discourses of “custody,” “training,” and “education” were transformed into a set of practices and techniques, and all inmates were subjected to a form of disciplinary power that both characterized and justified the institution’s existence.

While it might seem that “static cases” would have been out of place in the new “schools” for the “feble-minded,” their presence was explained and justified in a number of ways. First, it was argued that families could not handle the burdens of a feble-minded child, particularly the financial burdens. As Walter Fernald, the superintendent of one institution, writes, “Home care of a low grade idiot consumes so much of the working capacity of the wage earner of the household that often the entire family becomes pauperized. Humanity and public policy demand that these families should be relieved of the burden of those helpless idiots” (Fernald, quoted in Sloan and Stevens 1976, 26). Second, the institution could provide society with protection from a more menacing kind of feble-mindedness: moral imbecility. While possessing greater intellectual capacity than the lower grades of idiocy and imbecility, the “moral imbecile” was afflicted with a permanent moral defect. In his influential work on moral imbecility, Isaac Kerlin underscores the static nature of this condition: “We have individuals who, from some inherent fault in, or some radical defect of the receptive centers, are destitute in part and sometimes wholly of the so-called moral sense, and no environment and no education will supply the deficiency” (1976b, 307). These “static cases,” then, justified the existence of the institution as a *protective* instrument. The incarceration of “low-grade idiots” protected them from the injustice of being housed with the poor and the insane, and from being neglected and harmed in an unsuitable family environment. In addition, the incarceration of “low-grades” meant that the families of these burdensome cases of idiocy were protected from hardship and financial ruin. Furthermore, the incarceration of moral imbeciles protected the rest of society *from* them. The dangers of their immoral and criminal behavior and the possibility of their propagation were prevented by the custodialization. Finally, the institutions served a protective function for their superintendents themselves. In other words, there was a self-serving motive for the custodialization of static cases. In his history of the “low-grade” population, Ferguson argues that the institutional population of “incurables” was necessary to explain the superintendents’ failure to educate or improve many of their inmates and to reintegrate them back into the community (1994, 2–3). Thus, the superintendents were protected from criticisms of failure by the existence of unteachable cases within their institutions.

While the necessity of the institution was justified by the existence of these custodial cases, whose conditions were considered hopelessly static, the institution also relied upon and perpetuated the notion of feeble-mindedness as a dynamic condition. The assumption that feeble-mindedness was changeable lay at the core of the campaign to build institutions for the “feeble-minded.” The rhetoric of improvability and educability, and the belief in the importance of a proper environment, pervaded the calls for new facilities. The practices within the institution, which ranged from education and training to supervision and punishment, were predicated upon the belief that the proper environment could *improve* feeble-mindedness, and more importantly, make its victims *productive* individuals. Here we find the institution, not as a custodial, protective facility, but as a reformatory and productive one.

Despite the faith in the educability of the “feeble-minded,” which provided the impetus and justification for the new institutions, the notion of training, not education, dominated institutional practice. Most individuals living in institutions were subjected to rigorous training and supervision, the goal of which was *productivity*. Though some were taught to read and write, Fernald admits that “[t]he most prominent feature of our educational training today is the attention paid to instruction in industrial occupations and manual labor” (1976, 323). The conflation of education with training can be explained in terms of the *institutional need* for productive inmates. There was no hiding the economic advantage provided by the use of inmate labor. Fernald writes, “The average running expenses of these institutions have been gradually and largely reduced by this utilization of the industrial abilities of the trained inmates” (325). Though it was argued that both the mild and severe cases could benefit from “training,” it was the institution that ultimately benefited. In short, the educational nature of this labor cannot be separated from its institutional utility.

The institution relied upon both static and dynamic depictions of feeble-mindedness. In fact, a paradoxical relation between these two supposedly disparate kinds of mental retardation emerges, particularly when we look at the characterization of inmate labor. Outside of the institution, feeble-mindedness is considered incurable, hopeless, and dangerous, a condition that requires the institution to protect both those who have it, and society at large. Within the wall of the institution, however, the same condition is seen as improvable, and disciplinary techniques are employed to make inmates productive. An examination of the gendered nature of inmate labor provides an especially interesting example of this phenomenon.

As the definitions of feeble-mindedness shifted to reflect a close associa-

tion with immorality, giving birth to more than one child outside of a marriage became a “sign” of feeble-mindedness. This resulted in the incarceration of many “feeble-minded” women, who then served as caregivers for the “low-grade” inmates in the institutions. What is particularly interesting about this use of unpaid, inmate labor is that the very characteristics of femininity that these women had supposedly subverted outside the institution, justified this distinctly *gendered* form of institutional labor. While the “feeble-minded” woman was a danger to society by virtue of her procreative powers, inside the walls of the institution she could nurture and protect her surrogate children (see Carlson 2001).

Foucault defines “discipline” as “a type of power, a modality for its exercise, comprising a whole set of instruments, techniques, procedures, levels of application, targets” (1979, 215). He describes the development of this kind of power in eighteenth- and nineteenth-century schools, hospitals, factories, military schools, and ultimately, the modern prison. Foucault goes on to describe the prison as “omni-disciplinary”: “Prison must be an exhaustive disciplinary apparatus: it must assume responsibility for all aspects of the individual, his physical training, his aptitude to work, his everyday conduct, his moral attitude, his state of mind” (235–36). The institutions for the “feeble-minded” were “omni-disciplinary,” insofar as they monitored, studied, documented, taught, punished, and trained their inmates in the hopes of making them into useful human beings.

In addition, Foucault describes how “discipline produces subjected and practiced bodies, ‘docile’ bodies” (1979, 137). In the institutional world of feeble-mindedness one finds both docile bodies and docile minds. For example, Fernald writes, “In this ‘education by doing’ we not only have a very valuable means of exercising and developing the dormant faculties and defective bodies of our pupils, but at the same time we are training them to become capable and useful men and women” (1976, 323). Like the penal system, these institutions for the “feeble-minded” found as their “useful object” the “disciplinary individual” (Foucault 1979, 227). As Foucault remarks, “Discipline ‘makes’ individuals; it is the specific technique of power that regards individuals both as objects and instruments of its exercise” (170). Fernald’s characterization of the approach of “education by doing” hints at the *performativity* to which Foucault refers. While the “feeble-minded” were objects of various techniques and practices (for example, documentation, examinations, punishments), they were also called upon to take part in the workings of this disciplinary apparatus: they were taught to be productive so that they could work *within* the institution. The “feeble-minded” of all grades were compelled to take part in the functioning of the

apparatus for whom they were objects of study and contributing subjects. In Trent's words, "Educated feeble minds became productive feeble minds" (1994, 84).

I have examined institutional discourse and practice in terms of a series of oppositions between the qualitative and quantitative and between the static and dynamic. Though these portrayals of mental retardation might initially appear contradictory, they actually operated simultaneously in the world of the institution. These conceptual pairs influenced the creation of categories, the nature of practices, and were continuously invoked by the superintendents who generated "expert" knowledge about feeblemindedness. Yet, the institutional world did more than produce knowledge; it also produced a particular *kind* of human subject. Foucault says: "The prison cannot fail to produce delinquents. It does so by the very existence that it imposes on its inmates" (1979, 266). We must ask the same question of the institutionalized "feebleminded": to what extent did the structure of institutional life create their "feeble minds," rather than improve them? The institutions, as protective and productive sites of disciplinary power, perpetuated the view of feeblemindedness as both a helplessly static fate and an improvable, dynamic condition. Both characterizations were indispensable to the survival of institutions and to the production of docile minds and docile bodies.

### *The Visible and the Invisible*

In the early twentieth century, another equally significant method of gathering and organizing knowledge about feeblemindedness emerged. The IQ test, which was developed by Alfred Binet and Theodore Simon, was brought to the United States by American psychologist H. H. Goddard; and its importance to the history of mental retardation cannot be overstated (see Trent 1994, 155–68; also see Gould 1981, chaps. 5 and 6). The crucial role that the development of mental tests played with respect to mental retardation is somewhat ironic, however. Although the practice of administering IQ tests accorded a scientific status to the superintendents' classifications of inmates, the *epistemological authority of the institution* began to wane because it was no longer the primary site for the production of knowledge about mental retardation. As the use of tests became more widespread, advocacy of "parole," community placement, and special classes in public schools grew (Sloan and Stevens 1976, 116). In addition, this new "way of finding out" about mental retardation had a profound effect on the classificatory scheme itself. Taking as an analytic model Fou-

cault's discussion of the clinical gaze and his examination of the ways in which the visibility and invisibility of the object/subject changed medical perception (1994), we can see how the practice of mental testing for feeble-mindedness operated at three levels of visibility/invisibility: the social, individual, and etiological.

The incarceration of "idiots" in asylums that kept them far from public view was, in part, an attempt to render feeble-mindedness socially invisible. Yet a public gaze was simultaneously directed at them from within the walls of the institutions; they were often displayed as forms of entertainment for the general public, and "experts" were able to dissect them with a professional gaze that brought to light their defects. With the development of the intelligence test, this gaze extended beyond the institutions for the feeble-minded, to other institutions where feeble-mindedness could be found. Tests were administered in prisons, reformatories, the army, and schools, the conclusion of which was that feeble-mindedness was a problem that affected many beyond the institutional walls. The intelligence tests heightened the visibility of feeble-mindedness: countless prisoners, prostitutes, schoolchildren, paupers, and immigrants were identified as feeble-minded. The results of testing fueled a campaign against the dangers of feeble-mindedness by linking it to other social ills (criminality, sexual vice, alcoholism, pauperism), thus making it visible as a social problem (see Trent 1994). At the basis of this social visibility, however, was a more fundamental *invisibility* at the level of the feeble-minded individual.

The implementation of these tests gave rise to a new kind of feeble-mindedness: the "moron." Unlike the "idiots" and "imbeciles," who were relatively easy to identify and whose place had been firmly established within the institution, Goddard defined this group as the most dangerous class because they could go *undetected* in society. The success of mental testing in rendering "morons" visible to the public prompted further steps to be taken in treating the problem (for example, institutional segregation and sterilization as means of controlling the spread of feeble-mindedness). Whereas earlier emphasis had been placed on lower grades of mental deficiency ("idiots" and "imbeciles"), all attention became focused on the "morons," particularly due to the possibility that they would reproduce. In the words of Goddard, "[The idiot] is indeed loathsome; he is somewhat difficult to take care of; nevertheless, he lives his life and is done. He does not continue the race with a line of children like himself. . . . It is the moron type that makes for us our greatest problem" (1939, 101–2).

The IQ test was so successful in the United States because it was seen as an effective and scientific way of picking out this new type of individual



(the “moron”); in addition, the test was thought to offer a solution to the limitations of medical and pedagogical methods. Goddard, in his report “Four Hundred Children Classified by the Binet Method” (1976), echoes the limitations of purely medical classifications: “We should certainly emphasize here what is known to all of you, that the old terms of classification, while of interest to physicians, perhaps, are of no practical value to us” (364.). The practice of mental testing changed the very contours of the category, and the epistemic authority of the physician’s gaze had been supplanted by a new psychological means of detection. The IQ test, according to Binet, Goddard, and the many others who promoted it, provided a direct line to a defective intellect, which was the defining feature of feeble-mindedness. In contrast with the multitude of visible signs of mental deficiency that had failed to provide a clear picture of feeble-mindedness, the IQ test was able to definitively fix the level of this elusive, invisible, yet indispensable feature of our humanness: intelligence. In this sense, invisibility triumphed over visibility.

The final level at which mental tests affected the visibility of feeble-mindedness is at the etiological level. Thanks to the widespread administration of intelligence tests, and to prisoners in particular, it was confirmed that feeble-mindedness in the form of the “moron” (i.e., high-grade intellectual and moral deficiency) had a direct link to criminality.

So we have, as is claimed, partly from statistical studies and partly from careful observation, abundant evidence of the truth of our claims that criminality is often made out of feeble-mindedness. . . . Lombroso’s famous criminal types, in so far as they were types, may have been types of feeble-mindedness on which criminality was grafted by the circumstances of their environment. (Goddard 1939, 56)

From this passage it is clear that, in one sense, feeble-mindedness had become a more fundamental category: it was considered the *cause* of criminality. Thus, the advent of mental testing affected not only the practices surrounding persons labeled feeble-minded, but was central to the very definition and etiology of mental retardation. Here, however, we find a sharp departure from Binet’s original intent by Goddard and other Americans, a break that allowed the tests to flourish and remain the dominant source of knowledge about feeble-mindedness. While Binet and Simon are explicit about the fact that the intelligence test measures the *actual state of intelligence* and that questions of etiology and improvability are *not* within the domain of the IQ test (Binet and Simon 1980, 37), Fernald’s presidential

address to the American Association for the Study of Feeble-mindedness illustrates that these tests were put to the opposite use in America:

The theory and practice of mental testing and the discovery of the concept of mental age did more to *explain* feeble-mindedness, to simplify its diagnosis, and to furnish accurate data for *training and education*, than did all the previous study and research from the time of Seguin. (Quoted in Sloan and Stevens 1976, 108; emphasis added)

While Binet refused to use his tests to explain etiology or dictate treatment, the IQ tests in the United States became inextricably bound with hereditarian explanations of feeble-mindedness and with methods of controlling it.

“Defective germ plasm,” or “bad blood,” was responsible for mental deficiency, and was passed along from one generation to the next (Gould 1981, 163). Since this invisible substance could not be seen any better than could “intelligence,” techniques were devised to bring it to light. Intelligence tests and family histories could confirm the presence of the invisible cause (“bad blood”) and the invisible defect (“low intelligence”). Given this belief in the hereditarian nature of feeble-mindedness, a host of treatments and solutions were proposed. Sterilization, segregation, marriage restriction, and immigration laws were all enforced to stop the spread of feeble-mindedness. In fact, the two aspects of feeble-mindedness that Binet and Simon had hoped to avoid in development of intelligence tests—etiology and treatment—became the focal point of their use in the United States. The *actual mental state* of the individual seemed far less important than what caused this defect, as well as what was going to be done about it.

### *A Historical Ontology of Ourselves: Rethinking Mental Retardation*

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Generally speaking, Foucault’s archaeologies and genealogies were intended to be, among other things, histories of the present. . . . At its boldest, historical ontology would show how to understand, act out, and resolve present problems, even when in doing so it generated new ones.

—IAN HACKING, *Historical Ontology*

In *Discipline and Punish*, Foucault emphasizes that “[t]he prison should not be seen as an inert institution, shaken at intervals by reform movements.

The ‘theory’ of the prison was its constant set of operational institutions rather than its incidental criticism—one of its conditions of functioning” (235). The institutions for the “feeble-minded,” the professional organization now known as the American Association on Mental Retardation (AAMR), and the existence of IQ tests were significant means by which to produce and gather knowledge about mental retardation. Yet from their inception through to the debates that continue today, this category has been a highly contested one. From the earliest attention given to “idiocy” in the mid-nineteenth century to Binet’s attempt to provide a solid, scientific basis upon which to detect feeble-mindedness, there was never a conclusive definition of mental retardation. Mental retardation, as an object of knowledge, has never had a permanent residence in any one field; it has been, and continues to be, an object of medical, psychological, pedagogical, moral, humanitarian, and political discourse. And while this history of mental retardation is replete with contested definitions and calls for institutional reform, the question that Foucault asks of the prison can be applied to the persistence of mental retardation as a viable classification: “Is not the supposed failure part of the functioning of the prison?” Perhaps the continual contradictions, challenges, and complexities have in fact been instrumental in the perpetuation and the survival of the category itself. This question is not simply a historical one, however. Given the significant shifts in our understanding of mental retardation that have been prompted by medical and genetic advances, political movements, and philosophical problematizations of disability, Foucault’s work can provide an important framework within which to pose ontological, epistemological, and political questions to the contemporary incarnations of mental retardation as a classification.

One important Foucauldian avenue that merits further exploration is the relevance of “genealogy” to a critical examination of mental retardation. Foucault writes: “Three domains of genealogy are possible. First, a historical ontology of ourselves in relation to truth through which we constitute ourselves as subjects of knowledge; second, a historical ontology of ourselves as subjects acting on others; third, a historical ontology in relation to ethics through which we constitute ourselves as moral agents” (1997b, 262). In light of the above reflections, it is clear that each of these domains is relevant to an analysis of mental retardation. The epistemological shifts and underlying conceptual tensions within this category, the permeability of the boundaries that demarcated mental retardation amidst changing practices (most notably institutionalization and mental testing), and the multiple discursive formations within which truths about mental retardation continue to emerge, underscore the importance of a genealogical anal-

ysis that critically examines contemporary modes of defining the “mentally retarded” as objects of knowledge.

The above analysis of the relationship between institutional knowledge about “feble-mindedness,” the justifications given for disciplinary practices, and the power relations that constituted the subjects therein, provides an overture to a “historical ontology of ourselves” in relation to fields of power. As this historical analysis of the dynamics of institutional practice reveals, the very definitions of “feble-mindedness” and the view of inmates *as subjects* were intricately bound up with social, political, and economic factors. I believe it is imperative to consider how contemporary practices and institutions affect definitions of mental retardation and shape the lines that are drawn between “disabled” and “non-disabled.” A deeper analysis of “non-disabled identity” may provide a theoretical framework within which to expose the complex power relationships that have constituted the “mentally retarded” as subjects who both act and are acted upon in various ways (for example, medically, pedagogically, psychologically, genetically) and in various contexts.

Finally, Foucault’s call for an exploration of the ways in which we constitute ourselves as moral agents is an essential step in reconsidering philosophical work on cognitive disability. If one examines the distinct kinds of ethical questions that philosophers ask about mental retardation, there is an irony that must be explored. In many ways, philosophical discourse about “the mentally retarded” takes this group to be self-evident, unproblematic, and ahistorical; yet, at the same time, there is often a remarkable proximity between the formulation of contemporary ethical issues and those addressed more than a century ago. Philosophical questions such as “Do the mentally retarded differ from nonhuman animals?” and “Are the mentally retarded *persons?*” bear the mark of a complex history that must be carefully and critically examined.

A genealogical project of this kind is not without difficulties, however. In light of the complexities and contradictions internal to this classification, a genealogical analysis must take into consideration the enormous variation in the capabilities of individuals who are defined as “mentally retarded,” and acknowledge that certain individuals may be unable to participate in this form of philosophical and political discourse. Foucauldian analysis challenges one to interpret the history of mental retardation and current practices and categories in light of the power relations and games of truth that contributed to its definition and evolution. Yet a Foucauldian analysis need not lead to a denial of the lived realities of people who are labeled “mentally retarded,” experiences that may be the result of their actual cog-

nitive abilities, and/or the political, economic, and social consequences of being classified as “mentally retarded.” Rather, the promise of a Foucauldian approach lies in the unmasking of certain power relations that directly affect the extent to which certain voices are silenced, and exposing the dangers of defining and *speaking for* an entire class of individuals. Ultimately, Foucault’s work calls upon us to consider how the very existence of mental retardation *as a classification* affects the process of self-definition and conceptions of moral agency for individuals who are thus labeled and for those of us who fall outside the conceptual and practical confines of this classification. It is in this regard that I believe Foucault’s archaeological and genealogical texts can serve as important guides for philosophers and disability scholars alike.

#### NOTES

1. I am deliberately using the term *mental retardation*, though I am both aware of and support movements that contest the term. Insofar as I wish to provide a critical analysis of the history and tenacity of this category, and because the term is still used in certain contexts (for example, psychiatric and legal discourse), I will focus my discussion on “mental retardation,” understood as a historically constituted category.

2. Many historians divide the institutional history of mental retardation into three distinct eras: a period of optimistic institution-building, 1850–80; a shift from education to custodialism, reflective of the professional view that “deviants” needed to be sheltered from society, 1880–1900; and finally, an attempt through social programs and institutional restrictions to protect society from the menace of feeble-mindedness, 1900–1920. See Wolfensberger 1976; Stroman 1976; Trent 1994. In taking seriously the Foucauldian notions of continuity and discontinuity as presented in *The Archaeology of Knowledge* (1972), I will present an alternate interpretation of this history that focuses on two moments of discontinuity (institutional development and IQ tests), and a series of underlying tensions that are continuous throughout this history.

3. Kurt Danziger (1990) discusses the emergence of physiology as a new discipline.

4. The relationship between racial classifications and mental retardation is far too complex to address here. See, for instance, Noll 1995; and Borthwick 1990.

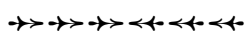
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JANE BERGER



## Uncommon Schools

### *Institutionalizing Deafness in Early- Nineteenth-Century America*

In *Deaf in America: Voices from a Culture* (1988), Carol Padden and Tom Humphries begin their exploration of the experiences of the contemporary Deaf community in the United States with a discussion of the way in which young Deaf children learn to assign meaning to the words *deaf* and *hearing*. One anecdote that the authors offer is particularly striking.

A Deaf friend of ours, Howard, a prominent member in his community, made a revealing comment to a mixed audience of hearing and Deaf people. All members of his family—his parents and brother as well as aunts and uncles—are Deaf. He told the audience that he had spent his early childhood among Deaf people but that when he was six his world changed: his parents took him to a school for Deaf children. “Would you believe,” he said, pausing expertly for effect, “I never knew I was deaf until I first entered school?” (16–17)

In Padden and Humphries’ discussion of Howard’s anecdote, they use the capitalized term *Deaf* and the lowercase term *deaf* to signify two distinct meanings of deafness. The capitalized term refers to the definition of deafness that Howard learned before he entered school. As one of only a small minority of Deaf people who have Deaf family members, Howard learned at home that deafness was commonplace and certainly not cause for alarm: it simply reflected membership in a larger American Sign Language–using community, many of whose members consider themselves part of a cultural and linguistic minority, rather than a disabled population. At school, however, Howard encountered an alternative way of understanding deafness that Padden and Humphries designate with the lowercase word *deaf*. He



became aware of what members of the Deaf community describe as the “pathological perspective” of deafness that posits deaf people as physically impaired by hearing loss, and thus in need of remediation and professional intervention (Kannapell 1991). This understanding of deafness differed radically from the one that Howard had taken to school with him and had shared with his peers.

The Deaf/deaf convention originates in the late twentieth century, and I will not use it in this chapter to describe nineteenth-century deaf Americans. Nevertheless, Howard’s insights that “deafness” has multiple meanings and that schools (or, institutions as they were called in the nineteenth century) are sites of both production of, and contestation over, the meaning of deafness are central to the discussion of this chapter. My argument is designed in the following way: first, I describe the iterations of deafness that were created by institution founders, educators, and others who supported the schools. I show how these groups assigned to deafness an array of meanings that were significantly influenced by intellectual, cultural, and religious trends of their time, as well as by the spread of market relations and emerging articulations of state sovereignty and liberal individualism. Then, I trace the responses of deaf alumni to the meanings of deafness that they encountered in schools, responses that were shaped by the new antebellum ideas about deafness. My primary concern is to indicate how hearing and deaf Americans communicated meaning about deafness through the ways that they organized space, movement, and time. In *Discipline and Punish* (1977), Foucault argues that the organization of space, movement, and time in institutions such as prisons, hospitals, and schools has the effect of disciplining inmates, patients, and pupils. In schools, for example, classrooms are organized so that students face the teacher and, therefore, learn to control their behavior in compliance with rules. Furthermore, the routinization of students’ movements and time accustoms them to relinquishing control over their schedules and bodies. Foucault explains that this regime primes pupils for political obedience and economic utility. While institutional organization during the early nineteenth century had these disciplining effects on deaf students, it served an additional function. As I show in this chapter, disciplinary effects were also produced by the messages that institutional organization conveyed to deaf students about what it meant for them to be deaf.

I make these claims about early institutions mindful that many scholars and members of the Deaf community consider the antebellum period to be the golden age in the history of deaf education. By 1860, there were twenty-three residential schools for the deaf in the United States (Fay 1893). In the

schools, deaf people who had previously been scattered throughout communities came together, learned sign language, and began to understand themselves as members of a group, with common interests. Enriched by their school experiences, some alumni went on to found institutions, or become teachers in institutions.<sup>1</sup> After the Civil War, however, hearing educators in schools for the deaf attempted to ban the use of sign language in favor of teaching spoken English and lip reading. In addition, hearing administrators largely replaced deaf teachers with hearing teachers (Baynton 1996; Buchanan 1993; Lane 1989; Van Cleve and Crouch 1989). By comparison, the earlier period appears idyllic.

Though there is much to celebrate about the early years, scholars such as Owen Wrigley (1996) and Phyllis Valentine (1993) have shown that there is also a danger in romanticizing the antebellum period. That sort of idealizing leads to inaccurate history; it also risks obscuring the power relations that were created in early institutions, some of which remain potent today.

For many deaf youth during the first half of the nineteenth century, the trip to the institution for the deaf probably involved a good deal of mystery. Most deaf children had hearing parents, and no one in their respective families (including the children themselves) knew sign language. As a result, parents were unable to communicate to their children the destination of their journey, and, as Henry Camp, a deaf nineteenth-century educator, noted, “[C]hildren set out for the asylum with little idea of where they [were] going” (1849, 78). As they traveled to institutions, many deaf youth probably wondered anxiously where they were headed. Encumbered by luggage and supplies as they left home, deaf youth may also have nervously pondered how long they would be away from family and friends.

The journeys to deaf schools were lengthy for many families because few of them lived within the vicinity of institutions. The vast majority of Americans lived in rural areas; yet most institutions built before the Civil War were within, or on the outskirts of, cities or large towns (Fay 1893). Institution founders took several practical factors into consideration when selecting school locations, such as a locale’s accessibility by public transportation. Cultural considerations were equally important factors, however. Because widespread institutionalization in the United States occurred during the antebellum period, some historians have suggested that mid-nineteenth-century cultural values influenced institution builders to locate campuses outside of urban centers, which many antebellum reformers associated with vice and decadence (Winzer 1993). In fact, institutions were more often built in urban areas, and it is useful to recall that the first schools for the deaf in the United States (those that served as models for the schools

that followed) were built during the early national period, a time when reformers considered cities the showplaces of national culture and achievement (Brown 1995). Experiments in deaf education, which many reformers considered to be on the cutting edge of scientific achievement, warranted prominent sites. Cities, which attracted the nation's early elite tourists (Brown 1995), were the logical locations for deaf institutions, most of which were features of urban landscapes during both the early national and antebellum period.

In part, reformers considered deaf education to be a progressive enterprise worthy of prominent urban locales because they believed that deaf education represented the application of modern science and reason to human improvement. Efforts to formally educate deaf people began in Europe as a product of Enlightenment-era interest in the workings of the human mind. Philosophers believed that the nonverbal thoughts of deaf people, who largely lacked access to spoken language, rendered them near cousins of "natural man" and thus worthy "objects" of study (Wrigley 1996). This interest in deafness was part of a larger epistemological transformation in Western thought during which men of science began to objectify the body and distinguish among the masses based on bodily characteristics (Foucault 1973, 1978). Philosophers, and in turn educators, identified deaf people as a group that was united by a common deficit that could be remediated in an institutional setting. The notion of singling out deaf people and segregating them was unprecedented, however, for institutionalization was unheard of prior to the period of the Enlightenment.

During the second decade of the nineteenth century, deaf institutions excited American emulation. Determined not to appear outdone by their European counterparts, American reformers sought prominent urban locations for new institutions. They also traveled the countryside to find students for their new schools. With time, most deaf youth who journeyed to the schools came to value their institutional experience; however, it is unlikely that the students immediately shared the enthusiasm that educators had for the new residential schools. Rather, students may have been most impressed by the eventual realization that those around them believed there was something so significantly problematic about deafness that it warranted a deaf student's removal from home and segregation in a distant urban institution.

Just as founders gave meaning to deafness through their decisions about where to locate institutions, they communicated meaning about deafness through the design of institution buildings. As I have already noted, during the early nineteenth century deaf children often set out for school unaware

of their destination. Indeed, they were probably still unsure of where they were when they finally arrived at the institutions. Deaf children who were familiar with common schools would in particular have had difficulty determining the function of the large and imposing buildings of the institutions, which bore little resemblance to local schoolhouses. The buildings of the Virginia Institution, founded in 1839 and one of several antebellum schools that served both deaf and blind students, suggest further cause for confusion and perhaps intimidation. These buildings, which had been constructed in the style of the Greek Revival, were described by a principal of the institution in this way:

[They] consist of a main center edifice, with a beautiful portico ornamented by six fluted columns of the Doric order, and of two wings four stories high, each with a covered piazza ten feet wide and sixty feet long, for the exercise of the pupils. There are besides, two wings running back toward the north, and two detached buildings fifty-three feet by thirty-five feet, three stories high. . . . A building of eighty-four feet by fifty-four feet is in the course of erection. (“Virginia Institution” 1854)

Other institutions were similarly as ostentatious, causing even some educators to question their excess. In an article that appeared in the *American Annals of the Deaf and Dumb* (the first deaf-related publication in the United States) in 1853, educator S. B. Cheek asked:

Are our buildings ever larger and more costly than necessary or proper? Can good reason be shown, why the state should put up finer schoolhouses for her mute than for her speaking children? Or, if larger and more commodious buildings are judged to be necessary, need they be made to rival in size and appearance the colleges, universities and largest public buildings of the country? (174)

Cheek’s query is an interesting one. What explains the extravagance of many early institutions that, though generally originating in small rented quarters, quickly grew into large campuses with multiple and elaborate buildings? The answer to this question can be found by considering the religious and political motivations that led charitable Americans and state governments to financially support deaf institutions.

As I have already indicated, enthusiasm for deaf education was in part the product of Enlightenment-era scientific curiosity. Yet religious concerns stimulated more interest in deaf education in the United States than

did science. Early schools for the deaf in the United States were built during the Second Great Awakening, a Christian revivalist movement comprised of participants who anxiously awaited or were eager to hasten the millennium. The Great Awakening stirred participants' interest in deaf people in two ways. First, leaders of the movement emphasized conversion. Intent upon spreading the word of God, evangelists sent missionaries all over the world to convert heathens to Christianity. In addition, they identified deaf people as among the cohort of souls who were ignorant of the word of God.

Reverend Thomas Hopkins Gallaudet (a Yale graduate who had studied under Timothy Dwight and who was one of the founders of the American Asylum, the first school for the deaf in the United States) was among the first to discover that deaf Americans were living in spiritual darkness. After Gallaudet's institution was founded in 1817, he toured the Northeast to spread word of the school and to attract funds and students. In 1824, he traveled to Vermont, Maine, and New Hampshire, where he repeatedly impressed crowds with his "Sermon on the Duty and Advantages of Affording Instruction to the Deaf and Dumb." Gallaudet praised his listeners for their generosity toward missionary efforts overseas; he warned, however, that "there are some of the heathen;—long neglected heathen;—the poor Deaf and Dumb, whose sad necessities have been forgotten, while scarce a corner of the world has not been searched to find those who are yet ignorant of Jesus Christ" (Gallaudet 1824, 8). Gallaudet pressed his listeners to extend their largess to deaf people.

Alarmed by the prospect of souls in jeopardy, many Americans responded generously to pleas on behalf of the heathen deaf. They may have been moved to benevolence as the result of the second reason that the Second Great Awakening stirred interest in deaf people: the Awakening emphasized charitable acts. During the first half of the nineteenth century, the belief that good works done on earth increased a person's odds for eternal salvation grew in popularity among Protestants. This emphasis on the relationship between charitable behavior and salvation represented a shift from earlier theology in which salvation was understood as predetermined by God and thus beyond the control of individuals. Because participants in the Great Awakening linked their own salvation with good works, many may have regarded their contributions to institutions for the deaf not only as opportunities to rescue heathens; they may in addition have believed their donations to be ways to work towards their own eternal reward. Those donations to institutions enabled educators of the deaf to construct elaborate institutional buildings.

Evangelical Christians were not the only Americans excited by institution building. Lawmakers also supported deaf education by voting in favor of governmental subsidies for institutions. To excite interest among legislators in deaf people, early educators linked governmental political legitimacy to state-subsidized institutions. Before the first institution was built in the United States, rich parents sometimes sent their deaf children to European schools. Four decades after the Revolutionary War, and less than a decade after the War of 1812, founders of the institutions argued that Americans should surely not be required to seek instruction overseas. As Laurent Clerc, the deaf Frenchman who with Gallaudet helped to found the American Asylum, extolled to listeners in a speech that he prepared, and that was read before a group in Boston, “In Europe, each nation, however small, has an institution for the deaf and dumb, and most of the institutions are at the expense of the government. Will America remain the only nation that is insensitive to the cry of humanity?” (Clerc 2000, 10). This, and similar pleas, suggested that the United States did not deserve a place among nations unless it constructed deaf institutions.

Invocations of national pride became exaltations of state glory after the founding of the first few schools. In Ohio, legislators took heart that within twenty-five years of their admittance to the Union, and while the state was three-quarters forest, an institution for the deaf had been erected. Educators bragged that the institution was in place by 1827, that is, even before the state’s common school system was completed (Stone 1853, 239). Illustrative of the role institutions had taken as a marker of state legitimacy, the 1852 Ohio constitution stated: “Institutions for the benefit of the insane, blind and deaf and dumb, shall always be fostered and supported by the state. . . . [This truly] is the noble resolve of a sovereign State; an honor to the sentiment of humanity which gave it birth, a purpose which could originate only in a Christian land” (quoted in Stone, 239). Institutions became so important to state pride and legitimacy that as late as 1892 the superintendent of the Illinois Institution for the Deaf noted that over half of the expenditures of some states were used to finance institutions of benevolence (Gillett 1893).

The support of the general public and state for deaf education had multiple consequences, some of which both the families of deaf youth and deaf students themselves viewed as positive. Many Protestant parents, who were anxious that their deaf children receive religious instruction but were unable to provide it themselves, probably valued the spiritual guidance that educators imparted in institutions. Furthermore, many deaf students grew to cherish their religious training. Indeed, churches became significant

institutions in the deaf communities that alumni of schools would later create (Burch 1999). In addition, families and deaf youth valued the academic instruction that students received in institutions. Although Wrigley describes the involvement of hearing people in the lives of deaf people during this period as “a form of colonization” (Wrigley 1996), few progressive antebellum Americans would have disputed the value of providing state-supported education to deaf children any more than would contemporary Americans. The instruction imparted in institutions allowed deaf people to more fully participate in their local and national communities than they otherwise would have been able to do if they lacked access to education. It would be a mistake to understand institutionalization as a phenomenon unrelated to the increasing democratization of public life that was a feature of antebellum America.

Nevertheless, the proliferation of institutions for the deaf also had less clearly positive consequences. The widespread institutionalization of deaf youth profoundly influenced the way that Americans understood deafness. It has been difficult for historians to recover what life was like for Euro-American deaf people prior to the advent of institutionalization.<sup>2</sup> However, anecdotal evidence suggests that, though very likely socially isolated in communities where they lacked full access to spoken discourse, particularly in the Northeast, where the first institutions for the deaf were built, deaf people were likely to be fairly well economically integrated in their families and communities.<sup>3</sup> On farms where family members pooled their labor, deaf people no doubt pulled their weight and were valued as productive contributors. The rhetoric used by institution builders to garner enthusiasm from the public and lawmakers for schools invented for deaf people a pre-institution past that did not emphasize integration, however.

As I have already mentioned, Gallaudet described untutored deaf people as heathens to convince potential donors of the exigency of institutions. To this assertion, other antebellum educators added descriptors such as “brutes” and wretched “unhappy objects” (White 1821, 4; Circular 1818). Some educators even went so far as to describe untutored deaf people as beings outside of the species of humans.<sup>4</sup> Although founders of the institutions emphasized deaf people’s intellectual and spiritual potential (Miller 1819), they also uniformly described deafness as a calamitous tragedy. These claims exasperated deaf author John Burnet who, in 1835, described them as “highly colored and often exaggerated” (Burnet 2000, 41). The claims probably caused the parents of deaf children (some of whom were at the forefront of efforts to create institutions) to bristle defensively, for no evidence suggests that they considered deaf relatives to

be less than human. Nevertheless, embellished assertions about the consequences of deafness remained a tactic that founders used to convince potential donors of the urgency of institutions for the deaf. The rhetoric of educators described deaf people not as productive members of family economies, but rather as individuals whose physical “defect” was cause for significant alarm. This emphasis on bodily integrity reinforced emerging notions of American individualism that constituted each person as singly responsible for his well-being. In addition, insofar as solicitations from clergy for financial contributions to institutions often accompanied the rhetoric, this emphasis helped to constitute untutored deaf people as legitimate recipients of charity.

The connection between deafness and charity was not entirely new, for indigent deaf people had in earlier times been entitled to community-subsidized support. The spread of market relations during the early nineteenth century, however, corresponded to a shift in the criteria that many Americans demanded of legitimate charity cases. As historian Michael Katz (1989) notes, Americans increasingly viewed as suspect those who did not thrive in the competitive marketplace. Americans, in other words, began to understand poverty as symptomatic of personal failure. As a result of the shift in attitudes about the poor, Americans began to create sharp distinctions between “worthy” and “unworthy” charity recipients. Through their enthusiastic support of schools for the deaf, educators and those who contributed funds to institutions exempted deaf people from moral disapprobation, despite their “need” for charity. The recently popularized rhetoric of educators that invented deaf people as “heathens” and “unhappy objects” justified the inclusion of deaf people in the “worthy” category, despite the fact that the rhetoric did not necessarily correspond to reality. “Highly exaggerated claims” about deaf people, in other words, were used during the early nineteenth century to help forge the distinction between the worthy and unworthy poor. Lawmakers lent governmental weight to the distinction and contributed to institutionalizing the ideas about deaf people through their appropriations of state funds to institutions, which were officially categorized as charitable rather than educational enterprises.

The elaborate façades of institutional buildings were among the ways that antebellum institution founders, educators, those who made donations to institutions, and state governments organized space to communicate to deaf youth and to the general public that deaf people were legitimate charity cases. Large and commodious buildings embodied the rhetoric that deaf people (allegedly demeaned in earlier periods as less than human) had been discovered by both men of science and men of the cloth and were protec-



tively embraced by a generous public and benevolent state. Ironically, the institution buildings actually indicated more about those who contributed to their construction than they did about their residents. Antebellum historian E. Porter Belden wrote, for example, that the New York Institution was “an architectural ornament to the city” and “a monument to the philanthropy of its founders and successive patrons” (1851, 122). Ornate institutions immodestly proclaimed the benevolence of founders and educators, the generosity of donors, and the legitimacy of the state. Not surprisingly, therefore, institutions became popular sites of early antebellum tourism, tourism that, in turn, became yet another way that educators and the general public communicated their understandings of deafness to deaf people.

Guidebooks, which during the early nineteenth century were called “stranger’s guides,” led early visitors to deaf schools. In 1818, for example, merely a year after the New York Institution became incorporated, it was included in *The Stranger’s Guide to the City of New York* (Blunt 1818). Administrators at the institutions warmly welcomed guests. Reverend White of Pennsylvania invited the public to visit the state’s institution and “contemplate the interesting objects by whom [the principal] is surrounded” (1821, 9). Visitors could observe deaf students in two ways. Some schools offered public exhibitions on a regular schedule. In the 1820s, for example, Anne Royall joined “two thousand, at least” other spectators at one such exhibition in Philadelphia (Royall 1826, 224). Similarly, in 1847, interested parties could apply to the manager of the Pennsylvania Institution for a spot at weekly Thursday afternoon exhibitions (Tanner [1847]). Other schools allowed visitors to roam school facilities. In fact, concerned about the comfort of visitors, one prominent educator urged his colleagues at the first convention of the American Instructors of the Deaf and Dumb in 1850 to equip each institution classroom with three or four chairs for guests. These, he suggested, should be located on a platform in the front of each room (Gallaudet 1851).

The presence of visitors at institutions meant that deaf students were constantly called upon to perform exceptionality. At exhibitions, administrators choreographed student displays that H. S. Tanner, author of a stranger’s guide to Philadelphia, recommended to his readers as both “exceedingly interesting” and “truly astonishing” ([1847], 76). In classrooms, the presence of tourists (and even the specter of the empty chairs) transformed a student’s mundane recitation of lessons into a spectacle of the near miracle of deaf education. Foucault (1977) argues that in schools in general, educators’ control over students’ movements helps to tame students’ bodies. In institutions for the deaf, educators’ control over move-

ment had the added function of inculcating students with the meanings that educators and institution tourists attributed to deafness. As I will indicate below, deaf alumni rejected much of what they had been taught about the meaning of deafness (though some students no doubt relished exhibitions and classroom visits in which they were the center of attention and which added excitement to an otherwise routine school day). Nevertheless, because students were aware that their every skill was the cause of astonishment, this knowledge must have influenced the way that they understood themselves as deaf people and how they made sense of their relationship to the larger hearing majority.

The erection of institutions that segregated deaf youth far from home, the ostentation of institution buildings, and the presence of tourists in schools were among the ways that educators communicated early-nineteenth-century constructions of deafness to deaf youth. Among the lessons that students were taught in school was the notion that there was something seriously wrong with deaf people that rendered them charity cases from whom even the most mundane of accomplishments was considered an extraordinary achievement. Educators did, however, offer students a way to escape the stigma associated with charity: students could learn to excel at a trade. Vocational education was a staple in institutions from the start, and over the course of the century, educators lengthened the amount of time students spent practicing trades (Buchanan 1999).<sup>5</sup>

As I have noted, institution founders and educators appealed to the public and states for financial support by stressing the heathen status of deaf people. In addition, administrators warned that untrained deaf people posed an equally troublesome problem: they could become economically dependent on others. Though deaf people were likely economically integrated on family farms prior to and during the early nineteenth century, the emergence of capitalism in the United States corresponded to a shift in the relations of production that threatened to disadvantage deaf people. In competitive capitalist labor markets, educators feared that deaf adults might experience discrimination when seeking employment. Educators in institutions promised to train students in the manual trades and, as the act that incorporated the Pennsylvania institutions stated, “render them useful members of society” (quoted in White 1821).

Like notions of worthy and unworthy charity recipients, the kind of dependence that educators feared for deaf people was recent in origin. Earlier, in the patriarchal societies of the Northeast, most Americans took for granted their dependence on family members and neighbors. Although young men sought “competence” or independence through land owner-

ship, few imagined that it would be possible without the combined efforts of kith and kin. The spread of markets and the concomitant shifts in the patterns of production that accompanied the rise of capitalism led, however, to a new definition of independence in the late eighteenth and early nineteenth centuries. As the capacity to make contracts and labor for wages increasingly replaced economic relations based on mutual exchange, independence became associated with individual success in the competitive marketplace. Although family members and neighbors continued to depend on one another, their non-cash-based mutual aid was increasingly defined as extra-economic activity. As the definition of independence shifted, so too did the meaning of dependence. Rather than a dynamic that enabled community subsistence, dependence became a marker of deficiency. Institution founders feared that deaf people would be unable to achieve the new iteration of independence as discrimination might limit their employment prospects. The concern did not lead educators to undertake public education campaigns to prevent discrimination in the workplace; instead, educators sited vocational instruction as one of the primary functions of institutions.

Both deaf and hearing educators took pride in their rigorous programs of trades instruction. There are, however, three ways in which the merits of vocational education were marred by its increased prominence in institutional curricula. First, the increased time spent in vocational education corresponded to a decrease in time spent on academics. By organizing their students' time in such a manner, educators communicated the notion that students had aptitude only as manual workers. Second, the emphasis on vocational education created constraints on the deaf community that emerged from institutions. As historian Tricia Leakey notes, "When the vast majority of a minority group are skilled only in manual trades, the group as a whole holds little or no economic power" (1993, 85). The third consequence of the emphasis on vocational education was by far the most insidious one. Having participated in creating the discourse in which deaf people were described as charity cases, educators then suggested to students that becoming productive workers was the means by which they could throw off their stigma.

The ideas conveyed through the location, architecture, and size of antebellum institutions, ideas that were reinforced by the rhetoric of educators and the general public, had profound effects on deaf students. In 1850, at a reunion held at the American Asylum to honor founders T. H. Gallaudet and Clerc, deaf alumni repeated the claims that they had been taught by educators about the spiritual darkness from which they had emerged and

the great debt of gratitude that they owed school founders, benefactors, and state governments (Brown 2000; Spofford 2000; Loring 2000). Deaf alumni did have reason to feel gratitude. Educators had participated in creating a discourse that posited deaf people as pitiable and in need of charity. As I have already mentioned, however, educators had also provided their students with access to religious instruction and education, which were widely valued during the early nineteenth century, but to which deaf people had limited access outside of institutions. Foucault notes that “what makes power hold good, what makes it accepted, is simply the fact that it doesn’t only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse” (1980, 119). Institutions opened new spiritual and intellectual worlds to deaf people. For that, they were grateful.

Institutions also provided a space in which students (though ultimately under the authority of hearing administrators) created their own deaf world. While students new to institutions may have had difficulty identifying them as schools, the students had little trouble recognizing compatriots among their sign language–using peers and teachers who populated institutions. As Edmund Booth (deaf frontiersman, journalist, and chair of the committee that in 1880 established the National Association of the Deaf and Dumb) wrote of his arrival at the American Asylum, “It was all new to me . . . the innumerable motion of arms and hands. I was among strangers but I knew I was at home” (quoted in Lane 1989, 233). Institution founders and educators certainly exaggerated claims about the pitiable plight of deaf people who were deprived of institutional life. Nevertheless, many deaf people did feel largely excluded in the company of hearing people whose spoken language they could not easily access. By contrast, at institutions for the deaf, students participated freely in all activities. Deaf educator Camp noted, for example, that on the playground deaf students were “capable of joining, and leading, in all their exhilarating sports” (1849, 79). They also had full access to all communication in the classroom and chapel. Deaf youth built their own worlds in institutions. Although alumni may have expressed gratitude to educators, it would be a mistake to think that deaf people accepted wholesale the antebellum constructions of deafness that hearing people asserted.

It is difficult to recover the details of student life in institutions. The activities of alumni, however, are more easy to access. These activities reflect a community determined to combat prevailing stereotypes about deafness. They indicate that high on the agenda of deaf people was a commitment to self-sufficiency and a determination to throw off the stigma

according to which they were charity cases. For example, in 1854, four years after the first reunion at the American Asylum, members of the deaf community in New England gathered at the school to pay a second tribute to T. H. Gallaudet. On this occasion, the focus of the ceremony was the dedication of a monument to honor the pioneer educator. Recall that ornate institution buildings were themselves monuments to the benevolence and charity of educators, benefactors, and the state. The 1854 monument was quite different, for it was self-consciously financed exclusively by the deaf community, and planned, as well as designed, by deaf artists. To collect funds for the project, Clerc organized a group of deaf people that would eventually become the New England Gallaudet Association of the Deaf and Dumb, the first of many deaf associations in the United States. At the unveiling, John Carlin, an alumni of the Pennsylvania Institution, expressed excitement about the statement that the monument made about deaf self-sufficiency:

As there is much reason to believe that this is the first monument in the world that has ever been erected by a community exclusively deaf and dumb, how exquisite is the satisfaction with which we look upon ourselves as its founders! What a source of gratification flowing through our veins while we contemplate this glorious result of our silent labors. (1854b, 31)

With the Gallaudet monument, the deaf community proudly claimed the American Asylum as its own. By funding the venture entirely on its own, furthermore, the deaf community rebuffed popular contentions that deaf people were charity cases.

Deaf people did not limit their claims for deaf space to institutions, however. In 1855, deaf Georgian John Flournoy, who had studied at the American Asylum, called for deaf people to press Congress for land on which to form a deaf state that they would govern and represent in Washington (Krentz 2000; Van Cleve and Crouch 1989). The proposal prompted a series of letters that were published in the *Annals* in addition to a discussion at a meeting of the New England Gallaudet Association (Van Cleve and Crouch 1989). Overall, the respondents to Flournoy's scheme (most of whom were deaf) disavowed it as impractical. Though Flournoy's dream was dismissed by most educated members of the deaf community who participated in the debate and have left written records, Krentz suggests that others may have regarded Flournoy's vision as appealing. Whether or not

this is so, the proposal demonstrates the extremes to which some were willing to go in order to secure deaf political and economic autonomy.

While members of the deaf community may have been ambivalent about the proposal that they form their own commonwealth, few who married resisted the option of choosing a deaf spouse and forming a deaf household. Data collected at the end of the century suggests that the vast majority of deaf people who did marry during the antebellum period married other deaf people (Bell 1969; Fay 1898).<sup>6</sup> The high rates at which deaf people married each other are probably due in large part to language barriers between deaf and hearing people and cultural affinities among deaf people. It is likely too, however, that deaf people regarded as appealing the prospect of creating households that were beyond the purview of hearing supervision. They must also have relished homes that were outside of the potentially demeaning gaze of hearing people. Recall that educators had paraded deaf students before tourists. Refreshingly, in deaf households there were no spectators to express astonishment at the completion of mundane house-keeping activities. By marrying one another, deaf people carved spaces for themselves that were largely free of hearing intervention and condescension. Marriages between deaf people also enabled them to demonstrate a commitment to their own self-sufficiency.

Deaf people evinced a further commitment to self-sufficiency and rejection of antebellum stereotypes about themselves by working to expand the vocational options to which they had access. As I have explained, the curricula in institutions stressed vocational rather than academic instruction. By mid-century, two institutions had added “high classes” for those students who showed academic promise (Van Cleve and Crouch 1989). This addition was clearly not enough to satisfy the deaf community; on the contrary, some deaf people began to demand access to higher education. Among them was Carlin, who in 1851 complained that the lack of access to higher education condemned the elite among deaf people to “earn[ing] a livelihood by common manual labor” (49). Three years later, he followed up this remark with a proposal for a “National College for Mutes” (1854a, 175). Many people, both deaf and hearing, agreed with the venture that was realized a decade later with the founding of the National Deaf-Mute College (currently Gallaudet University).<sup>7</sup> Through their fight for a college, deaf alumni demonstrated that they would not be content with limited options for their intellectual and vocational advancement.

By the 1850s, a vibrant deaf community had emerged from institutions and had begun to challenge dominant understandings of deafness. The

existence of a strong community, however, does not mean that the disciplinary function of institutions had failed entirely. Although the deaf alumni who left institutions developed resistant ways of organizing their lives, driving their struggles was the desire to disprove the notion that they had learned from school according to which theirs was a calamitous lot deserving of Christian pity and charity. As a result, the antebellum deaf community appropriated the mainstream values of self-sufficiency and independence. By becoming productive workers and citizens, many strove to prove false early-nineteenth-century stereotypes about deafness. Ironically, however, productive workers and citizens are precisely what schools—both common and uncommon—aimed to create.

To consider the early nineteenth century as a golden age in the history of deaf education is to celebrate the community that emerged from institutions and defiantly challenged antebellum notions about the meaning of deafness. In addition, it is to celebrate the impulse to provide education to all children. For despite the disciplining function of schools, they can in addition be the gateways to rich worlds of knowledge. Such celebrations are warranted. The disciplinary role played by early-nineteenth-century institutions, however, also merits attention. As I indicate above, Foucault (1977) points out that schools in general perform disciplining functions by preparing pupils for economic utility and political obedience. Institutions for the deaf surpassed these disciplining functions. Institutions taught deaf youth that, although they were deficient, they might escape their stigma if they diligently conformed to mainstream values.

#### NOTES

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1. For more on the nineteenth-century deaf community, see Gannon 1981; Jankowski 1997; and Van Cleve and Crouch 1989.

2. An important exception to this generalization is Nora Ellen Groce's study (1985) of the deaf inhabitants of Martha's Vineyard.

3. Deaf alumnus of the American Asylum Edward Booth explained, for example, that he set out for school despite the protests of a family member who preferred that he stay at home to work on the farm (Krentz 2000).

4. The Pennsylvania act that incorporated the state's institution pledged that the school would "reclaim the deaf and dumb . . . to the rank of their species" (quoted in White 1821, 16).

5. So much did educators increase the stress on vocational education during the antebellum period that by 1876 it became an issue of concern among some educators.

That year, Edward Minor Gallaudet, a son of the founder of the American Asylum, felt the need to assert in an article in the *Annals* that the “intellectual and moral training of the pupils” (235) should be the primary function of deaf education. The same year at a conference of principals of American institutions, he proposed that the organization endorse a mandatory minimum number of hours students should spend in academic instruction. The group debated the issue and ultimately voted with Gallaudet that students should spend five hours in academic instruction, five days per week for nine months of the year (“Proceedings” 1876). Although the measure did pass, Phillip Gillett, the principal of the Illinois Institution, commented that “it [is] very difficult in the case of deaf-mutes to draw a clearly defined line of distinction between the value of mechanical instruction and intellectual training” (“Proceedings” 1876, 237).

6. Bell found that by 1854, 69.6, 74.3, and 80.8 percent of alumni from the Ohio, New York, and Indiana institutions (respectively) who married did so to other deaf people (1969, 16).

7. For more information on the founding of Gallaudet University, see Van Cleve and Crouch 1989; and Gallaudet 1983.

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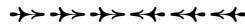
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DIANA SNIGUROWICZ



## The *Phénomène*'s Dilemma

### *Teratology and the Policing of Human Anomalies in Nineteenth- and Early-Twentieth-Century Paris*

On July 27, 1909, *La Femme homard* (The Woman with Lobster Claws), Mlle Brison, a twenty-four-year-old woman with syndactyly, was brought before the Parisian tribunal (Vautel 1909, 1; “Chronique judiciaire” 1909, 4; “Diable boîteux” 1909, 1). Brison had been accused of contravening the police ordinance of February 1906, which forbade the exhibition of living *phénomènes* (humans and animals with physical anomalies)<sup>1</sup> in fairs and carnivals, save those who, for exceptional reasons, had obtained a special permit. Clément Vautel, whose editorial on Brison and her “crime” had appeared in the Parisian daily *Le Matin* a few weeks earlier (July 1, 1909), regarded this regulation as an infringement upon the rights of individuals with physical “deformities.”<sup>2</sup> Vautel commenced his piece with the question, “Is the *Femme-homard* a *phénomène* or an *artiste*?” He ended the editorial in this way:

And so, the freedom to be a *phénomène*—our last—has been withdrawn. . . . We no longer have the right to be an *Homme-squelette* [Skeleton man], a *Femme-crapaud* [Toad woman], if it’s not by virtue of special authorization. . . . It was really worth it, wasn’t it, to have taken the Bastille. No more living *phénomènes*. . . . That is something that will obstruct the recruitment of parliamentary officials. In times past, it was a family blessing when the last born showed a disposition to become a monster worthy of being exhibited by Barnum.—And the little one, the jealous neighbors would ask, does he show promise?—Yes, the happy father would answer, he promises to eclipse the *Homme à la tête de veau* [Man with the Calf’s Head]! Alas! All is lost. The career of *phénomène* is

destroyed because the administration is decidedly hostile to all of its superiors. (Vautel 1909, 1)

Notwithstanding Vautel's satirical jab at government officials, his words paint a fairly accurate picture. For most of the nineteenth century, *phénomènes* such as giants, dwarfs, *femmes à barbe* (bearded women), *hommes squelettes* (skeleton men), *femmes colosses* (fat women), limbless men and women, and a host of human-animal combinations were a common sight on Parisian streets and in venues of popular entertainment. Although the number of *phénomènes* appears to have decreased in the decades after the French Revolution, the more relaxed politico-religious climate of the July Monarchy (1830–48) saw their return in droves. The new science of teratology (the study of congenital anomaly in humans, animals, and plants) established by Etienne Geoffroy Saint-Hilaire (1772–1844) and his son Isidore (1805–61) not only generated public interest; in addition, it fueled a market, one that both astute entrepreneurs and the ever-expanding “floating” population of *saltimbanques* (itinerant entertainers), vagabonds, and beggars in and around Paris sought to exploit.

In part, public fascination with *phénomènes* had to do with their “questionable” origins and natures. While the “humanity” of individuals with congenital anomalies was unquestioned by the time Vautel penned his editorial, this was not the case in the early and middle 1800s. *Ancien régime* belief in theological, supernatural, and preternatural explanations for congenital anomaly, such as sexual relations with animals (bestiality) and with demonic spirits, and the maternal imagination<sup>3</sup> continued, even after teratologists demonstrated that all such anomalies could be traced to biological and physical causes. The nineteenth-century French jurist Rauter, for example, was not alone in believing that because “monsters” (individuals with severe congenital “deformities”)<sup>4</sup> did not have “moral personalities,” that is, human consciousness, they had no claim to civil and juridical rights (Martin 1880, 178).<sup>5</sup> As defined by the regulations of civil law, the physical conformation of the human head was the determining criteria of human being. If an individual did not look “human,” with cranial and facial features determined to be the most important markers, s/he was not regarded as “human.” In short, causality for and perception of congenital anomalies continued to be intimately tied to visible physical appearance, despite teratological findings to the contrary.

The link between physical appearance and “human being” undergirds the paradoxical relationship between teratology's gradual “humanization” of individuals with congenital anomalies and the emergence of corporeally

based disciplinary regimes that enacted the very opposite. While the natural and regular laws of teratology proclaimed the biological fraternity of men and “monsters,” the pathologization of teratological variations and anomalies led to the theories and practices of degeneration, normalization, anthropometry, eugenics, and social Darwinism. As the Foucauldian gaze imposed increasingly stringent degrees of normality or abnormality upon individuals with physical anomalies, social and criminal deviancy became associated with corporeal anomaly, and the policing of those who were labeled as such increased. The “dark underside” of the law-discipline relationship<sup>6</sup> that Foucault exposed in *Discipline and Punish* (1979) applies equally well to the perception and policing of human anomalies. On the one hand, teratological evidence held that individuals with congenital anomalies were to be considered biological variants, that is, “different types of human beings,” not omens, devil spawn, Nature’s jokes, or the products of bestiality. On the other hand, however, the surveillance and policing of humans with congenital anomalies made them “less than human,” by identifying them as deviant or abnormal, and restricting or eliminating their livelihoods.

With respect to *phénomènes*, there is more to this trajectory than concerns about corporeal difference or public salubrity and security. While early-twentieth-century authorities were sweeping the streets of the City of Light clean of *phénomènes* such as the *Femme homard* Mlle Brison, the armless and legless *Artiste tronc* [Human Trunk] Kobelkoff continued to tour and perform.<sup>7</sup> As Kobelkoff’s name implied, he was not a mere *homme tronc* [human trunk], he was an *artiste tronc* (he painted, performed gymnastics, shot pistols, ate and drank, threaded needles, uncorked bottles, and signed his name). The same argument, however, did not hold up for Mlle Brison. Although Brison’s lawyer contended that because she too was an *artiste*—she staged sewing and embroidery demonstrations—the February 1906 ordinance did not apply to her; Brison was found guilty of thirty infractions and condemned to pay thirty francs in fines, one franc for each infraction (“Chronique judiciaire” 1909, 4; “Diable boîteux” 1909, 1).

The distinction made between *phénomène* and *artiste* is a rather curious one, since both Brison and Kobelkoff performed ordinary, everyday activities. While Brison was a street entertainer who exhibited herself in a small booth on the streets or in fairgrounds, however, Kobelkoff was a prosperous showman who owned one of the first *cinématographes* (traveling cinemas) in France. Was the difference between Brison and Kobelkoff a socioeconomic one? That is, were marginalized individuals such as *la Femme homard* (who exhibited in public space) deemed the detritus of

society, while well-off entertainers such as Kobelkoff (who performed in “theatrical” spaces) designated as legitimate? Or did the difference have something to do with the amount of talent or effort that one displayed, the amount of work and willpower that one needed to overcome one’s respective “handicap”? Was the difference between *phénomène* and *artiste* authentic performativity? That is, while *phénomènes*’ “performances” were thought to be simply pretexts for corporeal display, were *artistes*’ performances perceived as actual performances? Was mere corporeal display considered “illegitimate” labor? Just as the panopticon-like surveillance in prisons, factories, schools, and other institutions that Foucault (1979) analyzed were meant to forestall socially-unacceptable behavior and inculcate certain psychosocial norms, so too did the surveillance and policing of human anomalies serve to reinforce a newly emerging definition of the “human,” a definition that centered upon psychosocial, rather than purely corporeal, criteria.

The shift away from the purely physical definition of “human being” is readily apparent in the changing attitudes of Parisian authorities to two different types of conjoined twins. While Parisian authorities had banned the exhibition of both Chang and Eng (the original “Siamese twins”) and Rita-Christina, an eight-month-old *monstre bicéphale* (two-headed monster) in late October 1829,<sup>8</sup> Chang and Eng were eventually given permission to exhibit in France in 1835.<sup>9</sup> It is hard to say whether or not the about-face of Parisian authorities in this regard was due to the influence of Isidore Geoffroy Saint-Hilaire’s *Traite de tératologie* (the first volume of which appeared in 1832). Some fifty years later, however, the five-year-old Tocci brothers (Jean and Jacques), conjoined twins of the same type as Rita-Christina, were still not permitted to exhibit. In response to the request by Battista Tocci (the twins’ father), the head of the municipal police had stated: “I am not of the opinion that such monstrosities should be exhibited in public. They are purely the concern of the medical faculty” (“Exhibition” 1883).

While Chang and Eng (*xiphopage* twins) looked like two perfectly “normal” young men who happened to be joined at their abdomens by a thick fleshy band, Rita-Christina and the Tocci brothers (both *xiphodyme* twins) were united from the chest down. In other words, both of these sets of twins had one chest, one abdomen, one pair of legs, and so on; however, each set had two necks, two heads, and two pairs of arms. If compared to “normally” conformed human beings, Rita-Christina and the Tocci brothers each literally had two heads on a single body. Although the authorities’ concerns about the “unnatural” origins and natures of *xiphodyme* twins dissipated by the 1880s, they were still not considered appropriate viewing for

the general public. Despite the official veto, however, the Tocci brothers did exhibit, as had Rita-Christina (Véron 1883).

Even though some conjoined twins (such as Chang and Eng) and limbless individuals did not look particularly “monstrous,” Isidore Geoffroy Saint-Hilaire’s new teratological classification made conjoined (and parasitic) twins and limbless individuals the only viable “monsters.” All others who were classified as “monsters” by Isidore—for example, anencephalic (brainless), cephalic (headless), cyclops (one-eyed)—were still-born or died shortly after birth. While pre-1820s taxonomies of “monstrosity” relied upon conceptual frameworks that were organized around external physical conformation (thus rendering all visible deviations as “monstrosities”),<sup>10</sup> Isidore’s taxonomy made “monstrosities” only a subset of congenital anomalies, with the terms themselves (i.e., *monstrosity* and *monster*) having quite precise meanings. (In Isidore’s scheme, *monstrosities* only referred to severe internal anomalies that were also manifested externally.) Interestingly, it was the pre-1820s, or as Isidore put it, the “popular” definition of “monster”—any individual whose physical conformation or features astonished and, almost always, repulsed the gaze of viewers (Geoffroy Saint-Hilaire 1832–37, 1:30–33)—that lingered on. Indeed, it was the individuals with minor congenital anomalies and variations (which Isidore had classified under *hemitéries*, *heterotaxies*, and *hermaphrodismes*) who began to be perceived as truly “monstrous” by authorities and public alike.

Bénédict Auguste Morel’s theory of degeneration (presented in his *Traité de dégénérescences physiques* 1857) held that despite positivism and progress, humans (in particular, the “dangerous” and working classes) were physically deteriorating. Afflicted with visible corporeal signs that attested to their degeneration, these “degenerates” passed on their “sins” to their offspring, each generation progressively regressing until the stock died out (Davaine 1875; Pick 1989). Compared to the teratological definition of “monstrosity,” the visible physical markers of degeneration were relatively minor physical anomalies:

The head is too big or too small, irregular in its shape; the forehead is low and receding; the base of the skull is flattened; the parietal bone [back of the skull] is too prominent; the ears are badly placed and deformed; the upper jaw/teeth too big; the nose enlarged; the lips big and prominent; the facial features irregular; the physiognomy is disagreeable; the upper and lower limbs are disproportionate; the body is badly balanced. (Davaine 1875, 218)

The internal and sexual organs could also be affected; and hence, reproduction. The overall physical effect was largely a disruption of corporeal symmetry. As concepts such as “abnormal” and “anomaly” were assimilated first into teratological terminology,<sup>11</sup> and then public consciousness, corporeal symmetry took on much greater importance. With respect to *phénomènes*, this was most visibly evident in the slew of cute and symmetrically proportioned midgets who followed in the wake of Tom Pouce's (Tom Thumb) wildly successful tour through France in 1845.<sup>12</sup>

It was also after Tom Pouce's exhibitions that Parisian entrepreneurs began to actively exploit the public's fascination with human anomalies. For example, P. L'Henry, the former director of the Paris Opéra-Comique, wanted to open a venue that specialized in fair and carnival entertainment. His request to the Parisian police (February 1, 1846) stated that his centralized establishment would offer “all types of amusing curiosities from the Canard de Vaucanson to Tom Pouce [his name and persona were used as drawing cards], from the *baraque* [booth or hut] of Polinchinelle to tight-rope walking, all accompanied by a permanent orchestra and animated by elegant boutiques” (“Paris” 1846). In a subsequent communication to the police (February 24, 1846), however, L'Henry justified his demand by emphasizing that his proposed establishment would assist in the policing of *saltimbanques* and *phénomènes*:

Far from augmenting the number of *spectacles de curiosités*. . . , we would diminish their numbers by reuniting them into one;—by their centralization we will render surveillance easier and less onerous for the authorities;—we would fill a crucial need by disencumbering renters of *maisons particulières* [private houses], where most of these exhibitions take place, of the cares and dangers of opening untried, incommodious, or eccentric constructions to the crowds; to replace the ephemeral *baraques* that more or less jam the *voie publique* [public way], we would substitute a vast theater, which would conform to all the conditions of security and public order that that solicitude of the authorities require. (“Paris” 1846)

L'Henry was accorded his request, and the Bazar Bonne-Nouvelle opened in December 1846. The description and engraving in the January 9, 1847, issue of *L'Illustration*, as well as the admission prices—one and two francs, respectively—reveal that L'Henry's intended audience was not of the working classes (“*Courrier*” 1847). Astute entrepreneurs such as André-Martin Pâris, proprietor of the Café(-Concert) du Géant, however, soon



saw the working classes as another potential market. During the course of twelve years (1851–63), Pâris exhibited at least ten giants before the Café du Géant burned down on April 29, 1863.<sup>13</sup> The giant, appropriately billed, would be paraded around between the vocal numbers, his excessive height often being emphasized by juxtaposition with individuals of lesser stature (the female singers and/or dwarfs). Pâris and L’Henry were not alone in offering fascinated Parisians of all classes glimpses of human anomalies. Various types of large- and small-scale venues in the entertainment districts of the city, including the first *arrondissement* (the city center), the boulevards (Champs-Élysées, Temple, Italiens, Bonne-Nouvelle, Montmartre, and so on), and the passages (arcades) located directly off the boulevards or just to the south of the boulevard Montmartre, offered up *phénomènes* for public consumption.<sup>14</sup> *Phénomènes* could also be rented for private parties or viewings, at rather exorbitant sums.<sup>15</sup>

Public (and scientific) fascination with human anomalies most certainly resulted in an increase in the numbers of itinerant entertainers, beggars, and vagabonds who relied upon displays of corporeal anomaly. Not surprisingly, the “floating” population that roamed Parisian public space was subjected to increasingly restrictive regulations. Successive ordinances that targeted itinerant entertainers progressed from, in 1828, restricting the locations where they could practice their professions (Nusse and Périn 1878, 22) to, in 1831, further restrictions in locations and hours (Gisquet and Malleval 1831). Moreover, when these performers applied for permission to exhibit or perform, they were required to specify the exact profession that they practiced and to present a *certificate of bonnes vie et moeurs*, that is, a certificate of lifestyle and morals (Gisquet and Malleval 1831). By mid-century, police regulations restricted the mobility of itinerant entertainers outside of their declared region of residence (Persigne and Colles Meygres 1853). The extension of Parisian city limits in 1859 and the subsequent elimination of all of the local fairs and carnivals that had previously been held in the areas outside of urban limits proved to be a watershed in the regulation of human anomalies. In 1860, taking as its rationale the increase in urban disorder, disruption, insalubrity, and vulgarity, the municipal council decided to allow only fourteen annual *fêtes foraines* (carnivals). From 1860 to 1866, however, eight of these fourteen *fêtes* were suppressed. The remaining six were banned after a police edict of January 3, 1867.

The suppression of these local *fêtes*, along with the destruction of the boulevard du Temple (a popular entertainment district) in 1862 as part of Hausmannization, most certainly resulted in an increase of itinerant entertainers on the streets of Paris. Accordingly, calls were made to reform per-

missions procedures and permits.<sup>16</sup> The resulting *Ordonnance concernant les Saltimbanques, Joueurs d'Orgue, Musiciens et Chanteurs Ambulant*, dated February 28, 1863, contained several new stipulations. Not only were *saltimbanques* required to wear a medal upon which their names and permission numbers were inscribed “in a visible place when practicing their profession” (article 5), with their permissions “indicated on a booklet of 24 pages, which ha[d] to be reviewed by the Prefecture of Police every three months” (articles 6 and 7), there were two new clauses that specifically addressed physical “deformity” and anomaly. Articles 4 and 10, respectively, stipulated, “Requests from the blind, the legless (*culs-de-jatte*), the armless (*manchots*), cripples (*estropiés*) and other infirm people will not be considered,” and “It is expressly forbidden for *saltimbanques*, organ grinders, and ambulant musicians and singers to be accompanied by children under sixteen years old or by the blind, *culs-de-jatte*, *manchots*, cripples, or other infirm people” (APP 1863b). These categories encompassed most types of *phénomènes*. With almost no places left to (legally) perform or exhibit, *phénomènes* vanished from the few remaining fairs in and around Paris (Véron 1868, i).

If at first *saltimbanques* and *phénomènes* took refuge in the streets, owners of the emerging venues of mass entertainment (i.e., café-concerts and music halls) soon saw in them another source of revenue. Following Pâris' example, owners of these venues began to employ the “out of work” *saltimbanques* and *phénomènes*.<sup>17</sup> Unlike Pâris, however, who merely paraded his giants around between the vocal numbers, these *intermèdes d'adresse* (numbers without songs) in café-concerts and music halls were acts in and of themselves, that is, variety-type acts that ranged from acrobatic, athletic, and illusionary numbers, trained animals, pantomimes and marionettes, song and dance, performances by giants, dwarfs, and conjoined twins, and comic relief between numbers. Interestingly, *phénomènes* were already popular subject matter for café-concert songs. For example, the café-concert singer Thérèse's (Emma Valadon) theme song circa 1862 was “La Femme à barbe” (The Bearded Woman). Although Emma could not perform it in the appropriate costume, the sheet music was sold with an appropriate illustration (Caradec and Nohain 1969; Maffei 1986). After 1885, café-concert singers used various types of *phénomènes* to create personas that embodied their repertoires. Indeed, their successes were partially built upon their physical anomalies. For example, Brunin appeared as an *homme squelette*, Gustave Challier fashioned himself as a hunchback, and later the dwarf Delphin achieved a certain amount of notoriety (Romi 1950, 20–21).

The incorporation of actual *phénomènes* into café-concert and music hall entertainment in the late 1860s and early 1870s was only a boon to those who actually did have a real talent or very unusual anomaly to offer. These “legitimate” entertainers had to provide a “legitimate” performance, not simply position “a simple white cotton sheet in front of the *curiosité*” or enclose “not so rare *phénomènes* in a *baraque*, with a sign and a music band, and ask . . . two *sous* entrance fee” (Fournel 1888, 212). The emerging distinction between the respective labor of the *phénomènes* (mere corporeal display) and *artiste* (authentic performance), however, was not simply a question of market demand. Performativity embodied “legitimate” capitalist transactions, while the mere display of corporeal anomaly did not. Although begging, vagrancy, and disability had long been linked together (Thomson 1997, 35), the exhibition of physical anomalies took on a particular valence within the contexts of consumer capitalism. As a consumer spectacle in a market exchange economy, individuals who displayed corporeal “deformities” (their own, or those of others) sought to evoke certain types of reactions (for example, sympathy, terror, awe, horror, compassion, fear, mirth, and scientific interest) in exchange for monetary compensation. The object of exchange was thus the psychosocial reaction of the spectator, which was largely, if not wholly, determined by factors such as the (often manipulated) representation of the figure of the “deformed” mendicant or *phénomène*, socioscientific explanations for physical anomaly, and finally, socioeconomic-political assumptions with respect to what was acceptable in terms of labor, vagrancy, and corporeal display.

In a society that was becoming increasingly meritocratic and democratic, the figure of the “self-made” man began to serve as a model for bourgeois and working class alike. “Legitimate” socioeconomic success was achieved by hard work, determination, ingenuity, and willpower, not by trickery or scams. Duplicity played a crucial role. Employers and consumers did not want to be duped into paying for something they did not receive; yet workers and sellers did not want to lose in the exchange. What if physical anomalies were faked precisely in order to illicit the type of “fair” exchange—a product or service in exchange for the satisfaction of a need—required by the market?

It was after the Franco-Prussian War (1870–71) and the Paris Commune (1871) that representations of *phénomènes*, specifically armless or legless ones, began emphasizing the idea of the “self-made” man. For example, the reviewer G. Wathmann summarized the reaction of the French press and public to the armless *phénomène* Carl Unthan: “[Unthan] is one of the most striking examples of what will and energy can accomplish against nature”

(1890, 379). So too with the aforementioned *artiste tronçonné* Kobelkoff. As Guyot-Daubès wrote: “*Hommes-troncs* are thus not only curious examples of singular anomalies that are met with sometimes, but they illustrate also how some individuals by dint of patience, hard work and ingenuity, arrive at supplementing the organs that they lack” (1886, 115). Even representations of the outcast and marginalized *cul-de-jatte* (legless individual) or *manchot* (armless individual) were rehabilitated (Beaunier 1901, 1102).

Indeed, these ideas reflected the sentiments of “real” working-class French men and women who were “disabled.” In Paris and surrounding areas at the turn of the century, a number of workshops were set up under the slogan “*Le travail honore homme*” (work honors man) in order to provide paid work and housing to working-class individuals who had been “disabled” through no fault of their own (Darzac 1900; Oberic 1901). As Darzac wrote: “The unfortunate cripple had, until now, but two careers to embrace, or between which to choose: begging or death—since, I ask you, who would hire a *manchot* or a *cul-de-matte*”? (1990, 582). A number of men who were missing legs, moreover, advertised the plight of disabled workers by trekking across France, and organizing activities (such as races for one-legged men) and associations (“Match” 1895; “Course” 1895; X. 1908; Doury 1907).

While the abbé Sièges had defined the productive labor of the Third Estate as central to citizenship in 1789, there was little or no precedent for the transition from a society based on birth and privileges to one that was based on industry and money. The ostensibly meritocratic society that emerged, however, was paradoxically grounded in the processes of physical and social normalization. As teratological investigation advanced, humans with congenital anomalies who had previously been perceived as outside the workings of natural law were rehabilitated into the biological family of “man,” and the construction of the French citizen-human became increasingly a biopolitical concern of the state. Besides corporeal fitness, the idea of duty and labor was crucial to the concept of the worthy citizen-human. If mendicants were duplicitous cripples, and the display of “deformity” was unworthy labor, were *phénomènes* therefore duplicitous citizens? If social and criminal deviants, identifiable by their minor physical anomalies, were visible manifestations of the physical and mental degeneration of the French nation, were they really French citizens or even (French) humans? The policing of anomalous bodies grew even more stringent, culminating in the period just prior to World War I, when *phénomènes* such as *la Femme homard* Brison, who had exhibited with relative freedom in previous decades, could no longer do so in a living capacity.

## NOTES

1. The French term *phénomène* is roughly equivalent to the Anglo-American (*side-show*) *freak*. During the time period that I cover in this chapter, *phénomènes* included not only individuals and animals with corporeal anomalies, but also individuals and animals with extraordinary physical abilities or special talents. Since I only deal with humans who have (real or faked) corporeal anomalies, I use *phénomène* to mean only this.

2. I use terms such as *deformity*, *monstrosity*, *dwarf*, *giant*, and so on, in order to retain nineteenth-century terminology and conceptual distinctions.

3. The maternal imagination theory posited that the imaginations of pregnant women would be adversely affected by the sight of physically “deformed” individuals and animals, which would in turn adversely influence fetal development and result in “monstrous” births.

4. Used in teratological and medical literature until fairly recently, this term described an individual whose severe congenital “deformities” were externally visible as well as internally damaging.

5. Rauter included a ruling in his 1836 *Traité du criminel français* that stated, “Homicide cannot be perpetrated neither on a monster nor on a corpse” (1836, 2:7, quoted in Martin 1880, 178).

6. According to Foucault, law is the mask for discipline, i.e., the modern mode of power/knowledge, the former being the overt and generally acknowledged “rules” that govern a society, while the latter constitutes the covert but actual mode of “control,” discipline being enacted on society in a subterranean fashion by the disciplines, i.e., the human sciences and the professions, which ultimately base their authority on science.

7. Guyot-Daubès 1886, 113–15; Saltarino 1895, viii, 108–10; “Affichettes” n.d., Kobelkoff; Kobelkoff and de Falers 1912; Garnier 1968, 47, 332–35; Scheugl 1974, 20.

8. As “unnatural” beings whose origins were suspect and whose very appearance could cause physical anomalies in unborn children, Parisian authorities had banned their entry in late October 1829 (Wallace and Wallace 1978, 97, 145, 148; Martin 1880, 368), despite Etienne Geoffroy Saint-Hilaire’s official report (1829) and pleas. Similar motivations were behind the veto of Rita-Christina, who had been brought to Paris at the end of October 1829 (“Mostruosités humaines” 1829; “Nouvelles de Paris” 1829; “Histoire naturelle” 1829; Castel 1830; Serres 1832, 132; Geoffroy Saint-Hilaire 1832–37, 3:166–69; “Monstre” 1837, 415). Although the official reason that the Parisian police gave for not permitting Rita-Christina’s public exhibition was concern for the infants’ health, authorities’ real fears centered upon the potentially dangerous speculation by the public upon the nature of “man” and the “unnatural” origins of these twins (“Monstre” 1837, 415–16). Rita-Christina’s parents, however, were in dire financial straits; thus, they resorted to exhibiting their *monstre bicéphale* clandestinely in their dark and dank lodgings, an action that resulted in Rita-Christina’s death (November 23, 1829). Parisian authorities ordered that the bodies of the infants be buried or burned within twenty-four hours; furthermore, an autopsy was only secured with great difficulty (“Monstre” 1837, 416; Gould and Pyle 1897, 185).

9. Upon seeing them, the startled reviewer for the Parisian daily *La Quotidienne*

wrote, “These monsters, since we must call them by their name, are not monstrous at all. . . . One remembers that these twins born in that part of India situated between China and the Ganges, in the famous kingdom of Siam, in this country of free men were already offered to Paris; it has been five or six years since they were repulsed from France as monsters of Satan. All protests of Geoffroy Saint-Hilaire could not move the police” (Wallace and Wallace 1978, 148–49).

10. For example, Buffon divided “monsters” (that is, individuals with any kind of congenital anomaly) into three classes: *par excès* (with excessive parts), (2) *par défaut* (lacking parts), and (3) reversal or inappropriate positioning of parts. Blumenbach and Bonnet classed “monsters” into four groups: extraordinary conformation of some parts, extraordinary distribution of parts or limbs, missing parts, and more parts than usual. Meckel relied upon Buffon’s classification but added a fourth category, hermaphrodites. These are only some of the simpler classification schemes that abounded prior to the 1820s (Geoffroy Saint-Hilaire 1832–37, 1:72–77; Davaine 1875, 205–7).

11. The terms *abnormal*, *anomal*, *anormal* only began to appear in definitions of *monster* and *monstrosity* from the 1820s on (Tort 1982; Fischer 1986).

12. “Naine” 1846; “Marquise” 1846; “Causeries” 1850a; Ph. b. 1850a; “Paris” 1850; Ph. B. 1850b; “Revue parisienne” 1850; “Causeries” 1850b; “Théâtre” 1850; “Nain chinois” 1857; “L’Equipage” 1857; Busoni 1857. In Paris, Tom Pouce (the American Charles Stratton) appeared in nightly performances of *Le Petit Poucet* (a stage work after the fairy tale of the same name, but written expressly for him) at the Théâtre du Vaudeville (Dumanoir and Clairville 1845); exhibited in the afternoons from two to four at the Salle Musard (49, rue Vivienne), both solo and with the giant Joachim Eleiceigui; was presented four times to the royal family and court; appeared at Longchamps (the race tracks); took daily constitutionals along the Champs Elysées and Bois de Boulogne in his miniature carriage, and was further miniaturized and “cast in sugar, in chocolate, in gingerbread, in porcelain, in plaster, and in cardboard” (D’Albanès and Fath 1845, 158), as well as in other commodity forms such as sheet music.

13. Darthenay 1851; “Jurisdiction commerciale” 1856; Karl 1858; “Homme grand” 1886; Pougin 1888, 131–32; Simond 1900, 2:517–19, 607; Romi 1950, 10; Jando 1979, 18; Sallée and Chauveau 1985, 122.

14. For example, the Cirque Olympique put on stage works such as *Le Géant, ou David et Goliath* (1838) in which the Belgian giant Bihin starred (Thomas 1838; “Le Géant” 1838; “Cirque-Olympique” 1838b; “Spectacles” 1838; “Nouvelles des théâtres” 1838; Gautier 1838; Guinot 1838), the armless German *phénomène* Unthan first performed in Paris at the Cirque-Napoléon in 1870—he was a feature attraction, along with the midget Princesse Félicie, from February through April 1870 (J. D. F. 1870)—and the conjoined twins Millie-Christine were exhibited at the Cirque des Champs-Elysées in 1873–74 (D’Hennebaut 1873; “Nouvelles” 1873; “Chronique” 1873; Gérôme 1873; Touchatout 1873; Bertillon 1874; “Nouvelles” 1874; Tardieu and Laugier 1874). Cafés and smaller theaters that featured *spectacles forains*, *spectacles de curiosités*, *exposition d’objets curieux*, *spectacles* or *pantomimes grotesques* also abounded in these commercial areas. For example, two Italian-born dwarfs—billed as Laplanders!—were exhibited at the Théâtre des acrobates, the tightrope walker Mme Saqui’s establishment

on the boulevard du Temple (“Revue des tribunaux” 1832; Ginisty 1907, 53–54); the dwarf Mathias Gullia was exhibited at the Café de la Terrasse on the boulevard Bonne-Nouvelle (“Causeries” 1838); and various giants, among them the Basque giant Eleiceigui who was Tom Pouce’s foil in 1845, exhibited at the Café Mulhouse (no. 2, boulevard des Italiens) sporadically through the 1870s (“Inconvénients” 1849; “Revue parisienne” 1850; “Stop” 1850; Véron 1879; Anon. 1879).

15. For example, the microcephalic *métisses* Maximo and Bartolo, exhibited as the last surviving members of the lost race of Aztecs (the “Last Aztecs”) were advertised as being available for three hundred francs per hour during the day and one thousand francs for a soiree lasting from 10:00 P.M. until midnight (“Nouvelles” 1855).

16. Official letter to the Parisian prefect of police regarding the necessity of reforming permissions procedures and papers for *saltimbanques*, *bataleurs*, organ grinders, itinerant musicians and singers, January 6, 1863, Archives de la Préfecture de police, series DB, carton 200.

17. According to Jean d’Herbenoire (1923), this was how the *intermèdes d’adresse* (numbers without song), i.e., performances by *phénomènes*, acrobats, and gymnasts, were introduced onto the café-concert and music hall stage. However, the director of theater Camille Doucet’s 1867 *ordonnance* allowing café-concert owners to present their artists in costume, to stage pieces such as dramas, vaudeville, and comedies, and to integrate *intermèdes* consisting of acrobats, dancers, and other nonvocal performances into their programs, must surely have played a part. Prior to Doucet’s ordinance, café-concert singers could not dress in costume, musical accompaniments were restricted, and dancing and acting were prohibited (Fréjaville 1923, 7–8; Romi 1950, 20; Wild 1976, 254–55).

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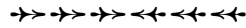
### III



## *Governmentalities*



ANNE WALDSCHMIDT



Who Is Normal?

Who Is Deviant?

*“Normality” and “Risk” in Genetic  
Diagnostics and Counseling*

Normality—that seems to be the central buzzword of our time. Don’t all of us want to be as normal as possible? Is there anyone who wants to be ostracized or considered deviant? Like ideals of health, the concept of normality has gained such great suggestive power, especially in the course of the last century, that one can hardly avoid its influence. In the government of deviance, normality has become the decisive point of orientation. Professional discourses and social policies, rehabilitation programs and therapeutic practices, all with the aim of making normality possible for their clients and recipients, revolve around this central notion.

At present, we are witnessing a substantial change in the way that society and the states in general, together with the persons concerned, negotiate the issue of deviation (see, for instance, Waldschmidt 1998). This shift in the negotiation of deviance relies upon a new conception of normality. Normality no longer implies conformity, but rather provides choices and leaves room for change. Indeed, it seems as if the notion of normality now meets the authentic needs and wishes of those people who are on the fringes of society. The line between normality and deviance is no longer rigid, or regarded as naturally given; it is shifting and variable, and is often seen as unnecessary. In today’s “normalization society,” normality is no longer considered an immutable, permanent fact-of-the-matter; instead, it is seen as a challenge, as something that can be designed and produced, as a phenomenon that changes with time. Normality is no longer an external constraint that society imposes on its members: it is

formed and shaped by acting subjects themselves. The conception of normality that currently prevails could, in other words, be termed *flexible-normalistic*.

What does *flexible normalism* mean? I use this term to refer to the theory of “normalism” that has been developed by the German literary scholar Jürgen Link (1996), who was himself influenced by the work of Foucault. When Foucault (1983, 1991, 1999) outlined his concepts of governmentality and biopower, he stressed the importance to these concepts of a statistical conception of normality that contrasted with the juridical norms that earlier sovereign forms of power had employed. He also called attention to the “apparatuses of security” (Foucault 1991, 102) that are necessarily installed inside of a power that governs primarily by freedom, not repression, and that reigns over people by regulating and positioning them, not excluding and institutionalizing them.

Even in neoliberal society, freedom is not boundless; freedom in neoliberal society is restricted by a logic of security that ensures that personal autonomy is used in a certain way. Moreover, just as freedom corresponds with security, the coin of normality has a flipside. Normality is concomitant with “deviation,” which will always be produced so long as people with and without disabilities strive for normality and for a life in the heart of society. When we define ourselves as normal, we also simultaneously define who should be considered as abnormal in comparison to us (Canguilhem 1974). In other words, both freedom and normality have their drawbacks, their social “costs,” and their victims.

In this chapter, I use the example of genetic diagnostics and counseling to describe how normalization wishes can be harnessed and to indicate how the normalization that Foucault (1991) called “governmentality” is part and parcel of a new form of self-regime. Of course, the power of normalization is not manifested only in human genetics. Normalization strategies can be found in various areas of society. To my mind, however, the apparatuses of normalization that are applied in human genetic diagnostics and counseling highlight in a special way the impact that normality has already gained on our daily lives. Before discussing human genetics practice, I consider the implications of the concept of normality. In order to begin to explore the importance of normality in today’s society, I discuss the distinction between normality and normativity. Then I turn to consider the flexible normalization strategies on which, in my opinion, the current normalization society—or, more precisely, its forcefulness, its legitimization, and its modernity—relies.

### *The Normalization Society*

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Until the middle of the last century, normality was often facetiously equated with the normative. A person was considered normal if he or she fit in, obeyed the law, fulfilled social expectations without great resistance. Consequently, being normal was defined as behavior that was oriented to dominant norms. But can the normal truly be boiled down to this simple denominator?

When one takes a close look at today's societies (especially those located in the Western Hemisphere), one finds that they do indeed seem to function in a different way than they did in former times (such as the eighteenth and nineteenth centuries). This functioning, furthermore, seems to rely a great deal on normalistic patterns. As Foucault (1983, 1991, 1999) and others (see the contributions to Burchell, Gordon, and Miller 1991; and to Broeckling, Krasmann, and Lemke 2000) have pointed out, societies that are dynamic, individualistic, and pluralistic are oriented less and less to penal laws, sanctions, and external conformity, and are oriented more and more to diversity, statistical normality, and internal self-governance. Social norms have receded into the background of everyday life.

The normality of the majority (average) seems to be the putty that holds neoliberal society together in the face of flexibility requirements, disorientation, and atomization (Link 1996). Of course, social norms still exist that we must obey if we do not want to be penalized. Over the course of the twentieth century, however, statistical normality became a special phenomenon that now, like normativity, aims to influence human behavior. In other words, my claim is that there are now two types of norms that guide human action: *normative norms* and *normalistic norms*. The differences between these two conceptions of the norm concept can roughly be described in the following way.

*Normativity* refers to the power of social and legal norms that are imposed upon people. Normative norms orient people to external rules that they must follow or to which they must conform. Controlling mechanisms ensure conformity with social norms; deviation and disobedience are subject to penalties and sanctions. A normative norm could be described as a "point norm," that is, a regulation that is externally set and prescribed for individuals. In terms of its social function, normativity is aimed at the production of stability and conformity. Its purpose is to generate conformity, prevent deviation, and protect society from upheaval and chaos.

Normality in the narrower sense, that is, average normality, involves comparing people with each other in light of a standard. *Normalistic norms*



confront each person with the question: who, or how am I, or how do I behave, *in comparison with others*? This question makes reference to regular behavior, rather than rule-conforming behavior. Normality in this modern sense refers to the existence of behaviors or characteristics that are regarded as customary, and whose statistical documentation can become the basis of guidelines and standards. The conformity that normalistic norms demand is not conformity with external rules; it is conformity with other people. Statistical normality, as an ordering category, refers to the ongoing production of a mean or an average, that is, symbolic or factual production of normal distribution curves. The normalistic norm is a “range norm,” a spectrum of phenomena that is grouped around an average (Link 1996, 185).

The normalistic norm has external power over only some people; however, everyone always participates in the formation of normalistic norms. All of us are always involved in the establishment of normal distribution curves: the normal mean, the relevant transition zones, and the relevant periphery. Normalistic norms, in contrast to normativity, are less static and less oriented to stability; they are based on change and dynamics. Since normalistic norms are supported by statistics, these norms exist only in highly data-oriented societies.

In short, the central means of governance in normalization society is the statistically backed, comparative description of people, their behavior, and their characteristics. Value judgments do enter into this description—for example, judgments with respect to category formation, definition of standard deviations, and definition of mean-values. In addition, normality leads to evaluations and expectations, but only after the fact, as the result of the production of statistical means. Assessment is preceded by a supposedly objective, neutral description that is based on facts and figures. By contrast, established norms and values are the basis for social control and discipline in normativity. The central distinction between normative and normalistic expectations, therefore, is that they involve different sequences of social action and norm-setting. In the case of normativity, a rule that has been put in place—a social norm—generates the same behaviors on the part of many people: “I’m expected to behave this way and no other way.” In the case of normality, the same behavior on the part of many people leads to a normalistic norm: “Everybody (many) does (do) that, that’s normal.”

In other words, today’s power relations—the ways in which society, state, and people are governed at present—are based upon normalistic

norms. The apparatuses of normalization no longer exert repressive forces on us in the narrow sense. The apparatuses “merely” call upon us to orient our behavior to that which the majority demands of each of us; only in this way do they discipline. Perhaps we no longer even notice the subtle, dominating character of the normalization technologies. Completely voluntarily, in line with ideals of autonomy and self-determination, we orient ourselves to the middle of society, to average norms. We want to live the way that other people do; most importantly, we want to be “normal.” If we feel enjoyment in deviation, it is only because we want to “march to the beat of a different drummer”—but, only for a little while. By no means do we want to be permanently localized at the negative pole of the spectrum of a certain behavior or characteristic.

In my view, governance by normalization has become so influential (especially over the past three decades) because of its ability to redefine the concept of normality and to enforce normality in social practice via discourse, operative procedures, and policies organized around an identity. In order to illustrate the functional power of governance by normalization, I will follow Link (1996, 77ff.), who differentiates two strategies: *protonormalism* and *flexible normalism*. Protonormalistic strategies can be characterized as follows: They are strategies that are oriented to normativity, which build on a strict separation between the normal and the pathological, and permanently ostracize all that is deviant. Protonormalistic procedures function whenever disabled people are isolated and institutionalized, wherever the homeless are legally ejected from public facilities, wherever asylum seekers are interned far from society, wherever homosexuality is regarded as a sin, and wherever slower-learning pupils are considered naturally “dumb.”

Flexible normalization strategies are gentler and more permeable than protonormalistic strategies. Flexible normalistic procedures begin with the ideal of a “well-mixed” distribution of people within the social environment, a distribution that can always change. Flexible normalism follows the assumption that people reach the periphery of society by chance. Flexible normalization strategies allow people to leave boundary areas of abnormality and return to the center of society. Like protonormalism, flexible normalism separates the normal from the abnormal; with respect to flexible normalism, however, this separation is only valid temporarily and can always be redrawn. Flexible normalism does not constrict the normal spectrum; it permits the spectrum to be expanded out to the boundaries if necessary. The flexible normalistic field can be compared with a “landscape”

(Link 1996, 348ff.); it contains continuous normalities and movable normality boundaries. For example, flexible normalism permits disabled people, who have been ostracized for centuries, to move into normal apartments situated in normal communities; it permits lesbians and gay men, who have long been stigmatized, to maintain normal, open relationships; and it provides special counseling and therapy programs that are designed to help addicts reintegrate themselves into society.

As I mentioned above, the tendency toward flexible normalization is not only positive; that is, flexible normalization does not eliminate all ostracizing categories, all mechanisms that divide people into hierarchical groups. Instead, the imperative of “rearward binding” applies (Link 1996, 339ff.). Graphically, this mechanism can be described as follows: in expanding, in moving outwardly toward abnormality, the band that binds the normal center with the boundary zones must not break. Any threat that the entire normal field could dissolve would spark a backlash, a return to strategies that emphasize narrow normality zones and fixed boundaries. In other words, the normalizing society is tolerant and accepts many escapades; nevertheless, normality boundaries continue to exist and may not be heedlessly crossed.

### *Flexible Normalization in Human Genetics*



The example of genetic diagnostics can be used to show that governance by normalization now permeates all areas of society. Genetic diagnostics also gives prominence to statistical norms. Although conception, pregnancy, and birth are actually incalculable, ultimately unpredictable events, statistics and probability calculations play a fundamental role in human genetics. Francis Galton (1822–1911), the founder of “eugenics” (from which human genetics developed after 1945), used statistical methods. In human genetics, additional normalistic landscapes have developed that are based on fluctuation ranges, transition zones, and variably defined boundaries (Waldschmidt 2001). These landscapes serve as a framework for seemingly autonomous decisions. In human genetics, as elsewhere, however, normativity peeks out from behind the friendly face of flexible normalism. In cases of doubt (such as the process of deciding whether a child may be born or should be aborted), normativity is that to which one resorts. Only on second consideration does it become clear that such cases also involve decisions about what is normal or abnormal in our society.

Practices of human genetics do not officially employ the concept of nor-

mality (and, hence, deviation). Instead, they emphasize the concept of “risk.” What does “risk” mean? Historically, the notion of risk stems from the insurance business and is closely linked to the evolution of the welfare state, “l’état providence” (Ewald 1991, 1993) or, as Foucault (1991) would put it, with the rise of apparatuses of security. Careful consideration of the notion of risk shows that it is statistically defined; it is “a calculative rationality” or “a set of different ways of ordering reality, of rendering it into a calculable form” (Dean 1998, 25). As a statistical category, risk actually denotes the opposite of flexible normality. There is an important difference between normality and risk: whereas normality is based on quantitative data and the calculation of the average, risk implies a further operation, namely, probabilistic measurement. In other words, normality is a category that describes past and present; risk is a concept aimed at governing (managing and controlling) the future (Castel 1991; Weir 1996; Dean 1998). The category of risk transforms arbitrary events of human life into “accidents,” which can be statistically counted and subjected to a probability calculus. As Ewald writes, “Nothing is a risk in itself, but anything can be a risk; it all depends on how one considers the event” (Ewald 1993, 210). Not only accidents in the workplace, but “birth accidents,” too, can be made risks and can be managed according to the insurance rationality.<sup>1</sup>

While Lorna Weir (1996) has less than convincingly distinguished insurance risks, on the one hand, from epidemiological or clinical risks, on the other, I maintain that clinical risks share basic criteria with insurance risks. In the medical context, as well as in the world of insurance, the calculus of risk is undertaken on the basis of population data; as an effect of risk calculation, health is turned into a form of capital, “a type of economic activity” (Dean 1998, 26) that demands cost-benefit analysis. Figuring as a risk, ill health acquires a modality that involves negotiating options that can be made a matter of loss redistribution. At the clinical level, as well as at the actuarial level, risk socializes events. Once a certain “evil” has been converted into a risk, one can see clearly that the given misery afflicts not one individual alone; it afflicts a mass of people at the same time. Consequently, seemingly natural and uncontrollable events, such as disease and congenital impairment, assume the character of social facts and, as a result, legitimize social solidarity (and intervention). Risk also has individualizing effects, however. Indeed, risk has to a great extent been “de-socialized, privatized, and individualized” (Dean 1998, 37), especially in contemporary societies. To take the example most pertinent to my discussion in this chapter, applying risk categories to individual bodies is essential to the practice of prenatal diagnostics. In other words, risk management in human genetics can

serve as a good example of the current individualization of risk. Or, as Weir (1996, 382) puts it: “Clinical risk techniques . . . breach the distinction between disciplinary governance that acts on individual bodies and security governance that acts on populations.”

And risk is a normalizing technique. By comparing a personal risk with the “normal,” that is, “average,” risk, a particular position within the normalistic field can be defined. One acquires information about where one stands in relation to others: in the middle, in a transitional zone, at the negative or positive pole. Of course, one is also expected to draw a (proper) conclusion from this piece of information. That is exactly the task with which human genetic counselors are nowadays confronted. They must tie up the average individuality expressed in certain risk figures with the personal situation of a single client; at the same time, however, they are obliged to refrain from giving specific counsel. In the past, experts could give direct advice; in the days of neoliberal government, however, they may only help clients to identify their own positions in the broad terrain of normality and deviation.

In the remainder of this section, I describe three “landscapes” that human genetic experts use in order to help their clients carry out normalistic location. The three landscapes are the “family tree,” the “age curve,” and the “triple test.” A common feature of all three orientations is that each of them uses both the concept of risk and probability information.

For more than a century, the first normalistic landscape of human genetics—the “family tree”—has played an important role in genetic counseling and diagnostics (Waldschmidt 1996, 107ff.). Modern molecular genetic procedures have failed to make the family-tree analysis superfluous; on the contrary, current human genome research has increased the needs for extensive family studies. Even today, individual genetic diagnoses are only indicative diagnoses: the greater is the number of families that participate in a given study, the more reliable such findings become in a genetic sense. In family-tree analysis, a family is considered as an unit of blood relations and studied in terms of its hereditary structure. Family relations are drawn in a tree-like, branching arrangement. Beginning with the person seeking help, the family network is studied for evidence of genetic disorders in earlier generations. The resulting genetic family structure can in turn be used to identify regularities in the transmission of these disorders. In keeping with the hereditary rules discovered by Gregor Mendel, family relationships are translated into probabilities of occurrence (Schmidtke 1997, 57).

A sample case: A woman wants to know her risk of having a child with

muscular dystrophy, which is a sex-linked, X-chromosomal, recessive hereditary disorder. Both the woman's brother and uncle have contracted muscular dystrophy; thus, they are carriers of the trait. Since the gene that causes the muscular disorder is located on an X chromosome, the woman's mother must be a carrier. The woman thus has a 50 percent chance of having inherited from her mother the relevant X chromosome with this trait and a 50 percent chance of having inherited the relevant X chromosome without this trait. The risk to her son is 25 percent; the risk to her daughter is 0 percent. However, the daughter has a 50 percent probability of having inherited the relevant X chromosome from her mother; thus, she can pass on this trait to her sons (Schmidtke 1997, 58).

This example shows that family-tree analysis applies universal laws of heredity to individual cases. In any given case, an empirical risk is determined for a specific genetic disorder that "runs in the family." In the case cited, the genetic risk is a family risk that affects not only the given individual "at risk"; in addition, it affects the individual's relatives. Thus, family-tree diagnosis illuminates the situation of several persons at one time. In the family-tree landscape, the categorically systematized, graphic study of a network of blood relations is combined with expert knowledge about rule-governed transmission of genetic traits. Family-tree analysis brings genetic patterns to the fore. Once identified, such patterns support conclusions regarding the probabilities of further occurrence. Family events from the past are extrapolated into the future and evaluated as to their relevance for descendants. In turn, statistical extrapolation such as, "One of your sons would have a 25 percent probability of contracting the disorder" influences preconceptional behavior or, if the counseled is already pregnant, leads to use of prenatal diagnostics.

The "age curve" (the second normalistic landscape that is applied in genetic diagnostics) is used to statistically interpret a given pregnant woman's relationship to her fetus. While any pregnant woman can have a chromosomally anomalous baby, regardless of her age, the probability of such an occurrence rises beginning at age thirty (Schmidtke 1997, 70). Human genetics has carried out numerous surveys in order to determine the frequency of Down syndrome and other chromosomal anomalies in relation to all births. So-called age curves are produced by correlating these frequencies with the ages of the relevant mothers and plotting the correlation on a graph.

The practical relevance of the age curve is its use in regulating access to prenatal diagnostics. Age thirty-five functions as the threshold. Pregnant women who have reached the age of thirty-five have access to prenatal

diagnostics on a routine basis. By contrast, younger women must exhibit additional indications in order to have such access. The allegedly objective threshold of thirty-five, which was established in Germany in 1985 on the basis of a mathematical construction (Sperling 1993, 26), has resulted as “a medically sustainable relation between the procedural risk and diagnosis probability” (Schmidtke 1997, 131); that is, the age risk for Down syndrome was weighed against the estimated miscarriage risk of amniocentesis. For women age thirty-five or older, both risks are considered to be about 1 percent. In other words, the benefits of obtaining findings about the health of the unborn are weighed against the risk of losing a baby. The official definition of “age risk” also reflects the available laboratory capacities and the costs incurred by health insurance funds (Schmidtke 1997, 131). At first glance, the age limit seems to represent a fixed line of orientation. Yet a probability can be presented in any of a number of different ways. In this case, a counselor may describe the risk of Down syndrome to a thirty-five-year-old woman’s unborn baby in at least eight different ways (Scholz 1993).

1. Your risk is 1:370.
2. A child with Down syndrome is born in 1 out of 370 cases.
3. About 3 children in 1,000 have Down syndrome at birth.
4. The child has a 0.27 percent likelihood of having Down syndrome.
5. The child has a 99.7 percent likelihood of being healthy; only in about 0.3 percent of all cases will a child have the disorder.
6. In about 0.3 percent of all cases, the child will have Down syndrome, but in 99.7 percent of all cases, it will be healthy.
7. Your risk is far less than 1 percent.
8. In comparison with a woman twenty-seven years of age, who would have a risk of 0.1 percent, your risk is 2.7 times higher.

The age curve thus offers different possibilities for normalistic location. Depending on the individual risk description and personal risk-weighting involved, the age curve can certainly be flexible in principle. However, the age curve makes one of the pregnant woman’s personal characteristics—namely, her biological age—the central focus in determining the relevant genetic risk. The pregnant woman (the client) is expected to view her individual case in relation to the amassed statistics on correlations between mothers’ ages and babies’ “disorders.” Furthermore, the woman is expected to weigh the risk of having a disabled child against the miscarriage risk that

is incurred with the procedure of amniocentesis. Because the age-thirty-five boundary has been arbitrarily defined, the age curve has had the effect of encouraging rather rigid pregnancy management. In the course of the 1980s, the age limit of thirty-five proved increasingly constricting for prenatal diagnostics. The “triple test,” which I will now describe, was probably developed for this reason. Like the age curve, the triple test is used predominantly in prenatal diagnostics (i.e., is relevant primarily for pregnant women).

This third normalistic landscape is not a curve or a range; it is a statistical relationship of the type 1:100. The purpose of the triple test is to determine the risk of chromosomal anomalies, especially Down syndrome and neural tube “defects.” In the sixteenth to eighteenth weeks of pregnancy, the pregnant woman’s blood is tested for the presence of a certain fetal metabolic product and two pregnancy hormones. The three parameters are correlated with data such as the pregnant woman’s age and the duration of the pregnancy. With the help of a computer program, an individual average-value is then calculated. If this value reaches a certain threshold, an increased personal risk is considered to be present. In other words, the triple test cannot detect or rule out congenital impairments; the test simply specifies the risk that a given pregnancy will produce a disabled child (Schmidtke 1997, 120).

The measurement distribution is actually continuous; there is no sharp boundary between “normal” and “unhealthy” diagnoses. Rather, the boundary beyond which a genetic risk must be assumed has been arbitrarily defined. The basis that is used to designate the boundary is the average value for a thirty-five-year-old woman (1:370). Again, this boundary is not objectively justified; it has resulted from the aforementioned age indication that has historically governed access to prenatal diagnostics (Schmidtke 1997, 121). In practice, an unfavorable constellation of serum values for a younger woman results in an assumed 1 percent risk of having a child with Down syndrome. The personal risk for the younger woman would thus correspond to the risk of the hypothetical thirty-five-year-old woman. In such cases, the test provides a personal calculation in comparison with the statistical average risk for Down syndrome. The risk specification does not permit any conclusions, however, about whether the feared disorder is or is not actually present. This certainty can be attained only with the help of amniocentesis.

Ultimately, the procedure has been important primarily for reasons of professional policy. The primary purpose of the triple test has been to give an increasing number of younger pregnant women access to prenatal diag-



nostics. The test aims to screen all women under thirty-five for higher likelihoods of chromosomal anomalies, and in turn to guide the group of women who receive “positive” results into invasive diagnostics, along with older pregnant women who have already reached or exceeded the relevant age boundary. The triple test produces relative probability values based on an arbitrary definition. Furthermore, the test supplants the rather coarse age category and helps to determine the individual, personal risk; however, the presumptive specificity of the test collapses its normalistic landscape into a very abstract value. Nevertheless, the triple test is accorded both symbolic and factual validity, since it can lead to other examinations, especially invasive ones, if it has positive results.

*Subjective Interpretations of Genetic  
Orientation Landscapes*

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I have said all that I will say here about the genetic orientation landscapes that human genetics offers its clients. Now I would like to focus on the question of how female clients respond to these services, that is, how affected women deal with the probabilistic interpretive patterns. Are they able to practice the self-governance that the experts expect from them?

Of the three landscapes described above, family-tree analysis is clearly the normalization template that clients are most likely to understand—surely, primarily for the reason that the family tree has a long genealogical tradition, a tradition that has long played a role in everyday identities and practices. It is true that the genetic counselor must normally expend considerable effort in entering clients’ often unsystematic, experiential family knowledge into the family-tree structure (Hartog 1996, 166ff.). In consultations, introduction of family-tree analysis typically tends at first to confuse clients. Their answers to their counselors’ questions often show that they do not understand the point of the exercise. In some cases, clients refuse to provide information—for example, when the family knowledge in question is taboo. As such interactions proceed, however, the clients often adapt to the counselors’ perspectives. The clients accept the institutional pattern and are soon able to provide answers that contain the necessary information in compact form. Furthermore, they soon understand the importance of information about relatives’ sexes and health. In acquiring the relevance system of the human geneticist, clients acquire a sort of professional view of their own relations (Hartog 1996, 177ff.). During the

course of the consultation, they thus certainly succeed in locating themselves within this normalistic landscape.

The subjective way in which the second normalistic landscape (the “age curve”) is used exhibits contradictions. Clearly, objective risk plays a relatively minor role in decisions regarding prenatal diagnostics. As various studies have shown, women who choose diagnostic services do not do so because they wish to minimize an increased genetic risk. Their perception of the risk actually depends on their basic position regarding the diagnostic service. In other words, women who have a positive attitude toward prenatal diagnostics will be more likely to perceive any genetic risk.

The “age curve” and invasive diagnostic procedures impose the necessity of comparing qualitatively different risks—namely, the risk of giving birth to a disabled baby and the risk of a procedure-induced miscarriage. The more serious that a woman subjectively considers her 1 percent risk of having a chromosomally affected child to be, the more readily she will undergo the amniocentesis. A woman who generally accepts the procedure will perceive her 1 percent risk of amniocentesis-related miscarriage as less threatening than the numerically equal risk of having a baby with a genetic impairment (for a summary of these points, see Wiedebusch 1997, 140). In other words, women who undergo invasive diagnostics subjectively perceive a higher risk of having a disabled child, and they perceive the risk of the procedure itself as lower. Conversely, women who decide not to use invasive prenatal diagnostics consider the procedure’s risk of injury and miscarriage to be rather high (cf. also Scholz and Endres 1990, 25–26).

Many clients have great difficulty understanding the meaning of the “triple test,” the third normalistic landscape that I have introduced above (see Schmidtke 1997, 122). Obviously, many clients of genetic diagnostics believe that a “positive” result means the presence of an effective chromosomal anomaly in an unborn child. That is, most clients understand the “test positive” result to mean that the dreaded disorder is already present. In actual fact, a positive triple test indicates only a risk of approximately one percent. The “person at risk” usually views her individual value within the terms of binary and normative categories, however. The result of the test is interpreted not as a probability, but as the actual presence of an anomaly in the baby (cf. in this regard the interview statements in Nippert and Horst 1994). A recourse to other services (such as invasive prenatal diagnostics), in the hope of obtaining certainty, is then the next logical step. Summing up, the way in which clients deal with the triple test also shows that individual risk perception is obviously closely linked up with risk assessment—that is, a risk assess-

ment in which risk is mostly viewed as a threatening danger, and not as a quantitative, probabilistic category (Castel 1991).

### *Conclusion*

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On the basis of clinical and statistical data, clients of genetic diagnostics are offered a number of different “landscapes” with which to choose a normalistic location. They receive standards against which they can determine and objectivize their own personal risk. They are given points of orientation with which they can estimate their own degree of genetic deviation and normality. This information is provided along with a call to avoid risks, however. The government of hereditary “defects” is a way of establishing “security” within the incalculable procreation process and is closely linked with the imperative of self-governance.

In contemporary normalization society, human genetics makes use of flexible normality and the epidemiological risk concept in order to render hereditary laws transparent and functional enough to enable women to make “appropriate” decisions in their respective cases. In all likelihood, the demands of liberalism, that is to say, the need for impartiality has motivated the genetic counseling profession to use the risk concept. Especially in Germany, counselors seek to practice a nondirective approach in order to avoid any suspicion that they engage in the eugenics of the past (Waldschmidt 1996, 1999). The orientation of counselors to mean values and comparative figures aims to establish neutrality and objectivity within the counseling context. Female clients are expected to make and justify their decisions as rationally as possible; any need for the counselor to give guiding advice is to be eliminated from the counseling context. In short, the use of the normality-risk concept is a way of rationalizing and legitimizing the genetic counseling process and the resulting decision of the client. Without doubt, human genetic experts go to great lengths to develop normalistic landscapes and to offer these to clients in ways that provide them with guidance. Explicit advice is no longer needed within the counseling context; for the suggestive power of normality operates.

Moreover, the statistical normality-risk concept is certainly a useful way to relieve individual burdens. The fact that clients are not turned into subservient victims by the diagnostic and counseling procedure, that they are appealed to as autonomous subjects, and that gains such as emotional relief and heightened security are offered to them, may also account for the success of the counseling concept of risk. In terms of the notion of risk, the

“misfortune” that an individual client may encounter is no longer an unavoidable fate suffered by chance; rather, it is an “accident” of nature that occurs frequently enough that it warrants statistical calculation. In terms of probability calculations, birth anomalies are actually “very normal”—and can be avoided! In this sense, genetic diagnostics and counseling, like insurance institutions, operate as forms of “government by security” (Weir 1996, 379). On the other hand, as I have shown above, individual risk perception is closely tied to subjective risk assessment. Ultimately, orientation to probability calculations does not eliminate the basic problem linked with *selective* human genetics.

In the framework of genetic counseling and diagnostics, statistics and prognoses are presented to real people, people who face real decisions and constraints—women who must quickly decide whether they wish to carry an unborn child to term, or abort it. And, of course, the normality-risk concept and the entire (insurance) setting within which the risk is presented do not allow any doubt about what kind of decision is expected from the individual woman: the decision not to have a child with a congenital impairment. In short, even in the society of flexible normalization, selection through prenatal diagnostics continues to be routine practice. It is eugenics that remains on the agenda—a concept of eugenics that has undergone a fundamental transformation, because now it governs by means of normalization strategies, and appeals to one’s freedom and autonomy in an “insuring” way.

#### NOTE

1. In Germany, since the mid-1970s, human genetic counseling and prenatal diagnosis have been covered by the social security system (i.e., the health insurance system).

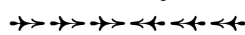
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MAARTEN SIMONS & JAN MASSCHELEIN



## Inclusive Education for Exclusive Pupils

### *A Critical Analysis of the Government of the Exceptional*

A number of authors have used Foucault's work (including his genealogical framework and notions of regimes of power-knowledge, normalization, and discipline) in order to reveal hidden dimensions of the practice of education (see Ball 1990; Marshall 1996; Popkewitz and Brennan 1998). In particular, theorists of educational practice have used Foucauldian tools to critique the segregated educational system, and the discourses about normal and abnormal students that surround it. Skrtic, for example, begins his *Disability and Democracy: Reconstructing (Special) Education for Postmodernity* (1995) with this remark from Foucault: "To find out what our society means by sanity, perhaps we should investigate what is happening in the field of insanity" (Foucault 1982, 211, in Skrtic 1995, xi). In order to do so, in fact, Foucault traces a genealogy of insanity back to Descartes, whose work precipitated a reign of reason that required the exclusion of unreason. Following Foucault's lead, Skrtic examines the historical figure of the disabled pupil and segregated (or, "special") education in order to consider what regular education means in Western societies. In short, the assumption that motivates Skrtic's work in this context is this: by tracing this form of educational exclusion to a certain moment in the past, we can historicize the allegedly universal principle of segregation and the conception of "normality" on which regular education relies.

It might seem impossible to repeat this methodological move with regard to the actual discourse on inclusive schools ("good education for all") and inclusive society, spaces in which everyone has a stake. After all, what is excluded from an inclusive school or inclusive society? What is the Other

of inclusion, an investigation into which would allow us to better understand inclusion in education and society? Does the very impossibility of raising these questions indicate that Foucault's work is itself a discourse of the past, useful only when the distinctions between "normal" and "abnormal," and "special" and "regular" prevail and are taken for granted? Let these puzzling questions serve as the horizon for our reflections in this chapter, reflections that have two aims.

First, we want to show that discourse on inclusion (in educational practice, in particular, and in society, in general) should be understood in terms of governmentality. Foucault uses the term *governmentality* to refer to a specific governmental technology; in addition, he uses the term to refer to a related governmental rationality that reflects upon the subject of rationality, that is, the practices of freedom—technologies of the self—through which human beings transform themselves into subjects (Foucault 1985, 1986). For Foucault argues that freedom, like power and government, must be brought into practice. There is no such thing as a freedom that is achieved once and for all. Furthermore, Foucault maintains that power and freedom are not mutually exclusive entities; rather, power and freedom are intrinsically linked with each other (Foucault 1982). In his work on governmentality, Foucault is concerned to show how this linkage is produced through the double bind of individualization and totalization that characterizes the modern nation-state, that is, how a free individual within a nation-state is simultaneously linked with other individuals into a totality. We aim to show that the discourse on inclusive schooling and inclusive society is an integral part of the history of this double bind, that is, an integral part of modern governmentality.

Second, we want to question this double bind and, therefore, the discourse on inclusion itself. That we want to question a discourse on inclusion—a discourse that rejects all forms of exclusion—might seem to imply that we wish to defend a kind of exclusion. This is certainly not the case. Rather, our central aim here is to think about education and society beyond the terms of exclusion and inclusion and the conception of "community" with which these notions are entwined.<sup>1</sup>

*"Omnes et Singulatim": The Individual,  
the Social, and Education*



One of Foucault's concerns is how societies, in the form of modern nation-states, are characterized by an ongoing governmentalization: the inclusion



of practices of freedom and, therefore, human subjectivity, in a network of governmental relations. For Foucault, the problem of rule in the modern nation-state is not “etatization of society”; rather, the problem of rule in the modern nation-state is the “governmentalization of the state,” through which human subjects become incorporated in a global, national context (Foucault 1991, 103). In order to become integrated into this structure, or totality, subjects must be formed through a specific kind of individuality.

I don't think that we should consider the “modern state” as an entity which was developed above individuals, ignoring what they are and even their very existence, but on the contrary as a very sophisticated structure, in which individuals can be integrated, under one condition: that this individuality would be shaped in a new form, and submitted to a set of very specific patterns. (Foucault 1982, 214)

In other words, totalization and individualization do not exclude one another. Under modern governmental strategies, they operate as related processes (cf. Foucault 1981, 1982). This double bind of individualization and totalization means that to be an individual, in the modern sense of the word, is to be linked to a totality. Again, our aim is to indicate how modern education—and its segregation—is linked with modern governmentality, in general, and with its characteristic double bind, in particular. In order to do so, we shall first make a brief historical excursion that is designed to explain Foucault's notion of “liberalism.”

From the perspective of governmentality, liberalism is not a political ideology that is incorporated into a political party, nor is it an economic doctrine; instead, liberalism is the name for a specific governmental rationality and technology. In general terms, liberalism is a reaction against governing too much (Foucault 1997). In a historical sense, liberalism is directed against the sixteenth- and seventeenth-century art of government, whose point of departure (so-called reason of the state) was the strengthening of the state. Sixteenth- and seventeenth-century territorial states established strong administrations, and their concern for power (both internally and externally) was related to mercantilism. On the terms of this governmentality, the state is never strong enough, and increased government is a necessity. Liberalism, in a negative sense, is a reaction against this government according to the reason of the state. In a positive sense, liberalism's point of departure is the assumption that there is a kind of natural reality with its own laws and dynamics in relation to which government has to

limit itself. In other words, liberalism as governmental strategy takes as its starting point a natural and independent reality that is comprised of different domains and limits itself in a critical way according to the features of these domains. These independent “domains of freedom” within which the free individual operates are referred to as the economy, the population, and civil society. Before the nineteenth century, when this liberal mentality comes to full expansion, these specific domains do not have a meaning, nor do they appear as objects for governmental knowledge and concern. Our goal is to show how “the social,” “the individual,” and “education” appear as correlates within the constellation of liberal governmentality, from which these autonomous domains could first be thought.

As a correlate of governmental strategies, (civil) society is a “natural” domain, with its own organization, which is comprised of individual human beings. Thus, problems for a governmental perspective could arise with respect to the relation between the individual and society—for example, problems regarding the distinction and relation between the human being as a person and the human being as a citizen, or tensions between the individual realm and the social realm. The basic assumption of the governmental perspective, however, is that free individuals live together and operate within society. From a governmental perspective, individual freedom does not exist as such, that is, as a kind of natural freedom; rather, freedom is something that must be formed in an active way within society, in accordance with the rules and norms of society. As Rose remarks, “Individuals . . . must recognize and act upon themselves as both free and responsible, both beings of liberty and members of society, if liberal government is to be possible” (1999, 68). Thus, individual freedom and the free domains within which that freedom is enacted are both effects of, and instruments for, liberal government (cf. Lemke 1997, 172ff.). For liberalism, insofar as it aims to govern through freedom, acts upon humans who are free in a particular way—that is, they bring their freedom into practice according to certain rules and, insofar as they are members of society, according to certain social norms. Rose summarizes it in this way: “Only a certain kind of liberty—a certain way of understanding and exercising freedom, of relating to ourselves individually and collectively as subjects of freedom—is compatible with liberal arts of rule, and that kind of freedom has a history” (1999, 33). Liberal government requires human beings who see themselves as subjects of freedom, who live together as individuals in a society. Within this configuration, in which specific discourses on “the social,” “the individual,” and the relations between them correlate with liberal government, “educa-

tion” becomes problematic in a characteristic way. In short, discourses on education become correlates of modern governmentality and thus enter a specific strategic space.

### *The “Governmentalization of Schooling”*

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Though we claim that education is central to liberal government, we do not mean that proponents of liberalism invented modern schools, nor that our modern educational system is the realization of their ideals. Following Hunter (1996), we want to understand the constitution of the modern school as a kind of “assemblage.” In order to motivate this approach to the machinery of the school, one must refer to forms of Christian pastoral power (which, for Foucault, is an early, though not strictly political, form of governing people) and the disciplinarian settings to which those forms of power give rise.

In the environment of early schools, the idea of a disciplined individuality and subjectivity was regulative and related to specific training practices. Ideals such as self-development and self-realization that were achieved through introspection and that followed fixed (religious) norms were part of the early schools. As Foucault stresses over and over again, this disciplinarian power in schools was productive: it produced a special kind of individuality, subjectivity, and freedom (see Foucault 1977). Liberal forms of government, accompanied by the increased governmentalization of the state, were able to use these disciplinarian settings as a “machine” with which to assemble civilization (Rose 1999, 72). Thus, it becomes possible to link the early orientation toward self-realization, self-development, and personal autonomy to components of civil society (such as social norms and civic virtues). Of course, certain tensions remained within this assemblage and governmentalization of the modern school; for example, the tension between a so-called religious, nonpolitical, orientation toward the good life and happiness, and a civic-liberal concern about civic virtues and further development of society. We will not, however, discuss these complex tensions further. Insofar as liberalism aims to govern through freedom (that is, free individuals *within* society), this freedom must be produced; here, then, is the place in which education will have a strategic position. One could say that as liberal government uses schooling as a tactic in its operations, there is a growing “governmentalization of education,” and the beginning of what could be referred to as the modern process of normalization through schooling. As much as freedom seen from the perspective of

governmentality has a history, so too is there a history of the “educated subject” (Fendler 1998, 39ff.). Through education, and in accompaniment with the governmentalization of schools, liberal government produces the free and educated individual, who exercises freedom according to certain norms, upon which it may act.

Because the governmentalization of schooling is an aspect of modern government, it should be clear that efforts to promote normality are a main feature of these processes, where normality means both what is typical, or average, and what is desirable for the individual. It is important to note here that in addition to the attention given to the schooling of the “normal” masses in the nineteenth and twentieth centuries, there occurs a concern for the schooling of disabled children. Deriving from philanthropic motives, the first initiatives in this regard date from the end of the eighteenth century; at the turn of the nineteenth century, however, this care comes to be carried out by a variety of experts, with the help of their objective gaze and effective treatments. This exclusion from normal education is not regarded as a kind of exclusion in an ethical or political sense, however; to the contrary, this exclusion is regarded as a necessary condition for offering an adapted form of treatment.

During the 1960s, this segregated educational system is questioned. This questioning can be understood if one considers government after the Second World War. By that time, “the social” has become a main concern for governmental strategies; “the social” is something with its own reality, which has to be defended by central government—the “social state” (Lemke 1997, 239ff.). In the postwar welfare state, the individual and the social are not exclusive entities, but rather are conceived as dimensions that are related to each other. Rose reminds us that “in the middle decades of the twentieth century, one sees the invention of the social individual, whose character was shaped by social influences, who found his or her satisfaction within the social relations of the group” (1999, 133). The belief prevails according to which individual freedom cannot be realized outside society, nor can social progress be achieved without regard for the individual. Within this governmental space, the exclusion of large groups of people, on the basis of (for instance) color, gender, disability, or sexuality, is not considered simply a matter of following professional expertise; to the contrary, exclusion of this sort becomes a highly moral and social-political problem. Politicians are not the only ones who define this kind of exclusion as a problem. This kind of exclusion is defined as a problem, first and foremost, by those who are governed in the name of the social and of freedom. This, then, is the his-

torical moment at which “disability” comes to be defined in a new way, a way that takes account of its social dimension.

In the late 1960s, Wolfensberger (for example) uses the concept *normalization* to refer to the activity “to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible” by the “utilization of means which are as culturally normative as possible” (Wolfensberger, quoted in Jenkinson 1997, 12). At a later point in time, Wolfensberger uses the less controversial term *social role valorization* to explain that normalization is “the creation, support, and defense of valued social roles for people who are at risk of social devaluation” (1983, 234). As these descriptions make evident, the point of departure for this conception is the social domain and the ways in which roles within this “normal” domain are valued. Thus, integration of disabled children in regular education in order to prepare them for normal society is preferred over exclusion and isolation of them in special schools. The transformation of societal perceptions with respect to devalued persons and groups is a correlative strategy of this accounting for the social dimension.

In addition, there was a growing consensus that what we regard as a “regular school” incorporated a rather narrow idea of normality, which excluded a large number of pupils from regular education. To put it another way, disability—as a kind of social disadvantage—was no longer regarded as simply a natural characteristic of human beings; rather, disability had come to be regarded as something that correlates with environmental factors and with what in society and regular education is seen as “normal.” In an influential article, Dunn formulates these sentiments in this way:

In large measure we have been at the mercy of the general education establishment in that we accept problem pupils who have been referred out of the regular grades. In this way, we contribute to the delinquency of the general education since we remove the pupils that are problems for them and thus reduce their need to deal with individual differences. . . . We must face the reality—we are asked to take children others cannot teach, and a large percentage of these are from ethnically and/or economically disadvantaged backgrounds. Thus much of special education will continue to be a sham of dreams unless we immerse ourselves into the total environment of our children from inadequate homes and backgrounds and insist on a comprehensive ecological push—with a quality educational program as part of it. (1968, 20)

These, and similar thoughts, are to a certain extent articulated in the American Education for All Handicapped Children Act of 1975, which states

that “handicapped” children should be educated as much as possible with their peers: “students with disabilities should receive their education in the ‘least restrictive environment’” (Jenkinson 1997, 16–17; Gartner and Lipsky 1987). The law and its effects aside, the language of the act represents the increasing influence of the educational environment. This general shift in emphasis becomes even more manifest in England and Wales at the end of the 1970s. In these contexts, the Warnock Report of 1978 (culminating in the Education Act of 1981) introduces the new notion of “special educational need” in order to get rid of the negative connotations that accompany notions such as “handicapped” (cf. Tomlinson 1982; Gartner and Lipsky 1987; Jenkinson 1997). What is more, the Warnock Report criticizes the traditional and stable medical categories that are used to classify pupils, proposes to situate every pupil on a continuum, and makes it possible for the regular school to take into account “special educational needs.”

To put it in a more general way, during the 1960s and 1970s there is a transformation in the attitude toward the principle of segregation in education that is related to social government and to a new understanding of disability. The politics of integration and mainstreaming (especially for pupils with mild and moderate disabilities) are grounded in the idea that we must educate pupils as much as possible in a normal setting, which takes into account their special learning needs. Placing pupils in special schools is increasingly regarded as a kind of exclusion (from normal, regular schooling, and, therefore, from normal social life), which is only legitimated as the final recourse—for example, when the goal of regular education is in danger due to a given pupil’s presence. Or to put it in more direct terms, by the 1960s and 1970s, isolating children in special schools becomes problematic and something that has to be legitimated, since individual freedom and identity are increasingly believed to come into being only in society.

At the beginning of the 1980s, however, a more critical discourse is developed that criticizes the principle of segregation as such and argues for inclusive schooling that takes into account the needs of all children, without prior distinction. Not restricted to education, this discourse on inclusion relates to society as a whole and, thus, correlates with changes in governmentality.

*Toward an “Inclusive Education” and an  
“Inclusive Society”*



The second half of the twentieth century is not only characterized by governing from the social point of view; in addition, that historical period is

distinguished by the emergence of critical discourses. In the terms of these discourses, social government and a strong state are criticized for the ways in which they destroy economic development and harness related forms of freedom. As Foucault points out, the main goal of neoliberalism is to govern economy as a domain of freedom and to reinforce society through this government (Foucault 1997; Lemke 1997, 239ff.). Of course, neoliberalism (as a form of governmentality) does not construe freedom as simply the freedom of the *homo economicus* of classical economy; rather, neoliberalism construes freedom in terms of an entrepreneur operating in a free market (cf. Rose 1996a, 1996b; Miller and Rose 1997). Furthermore, entrepreneurship is not just the name for an institution; instead, entrepreneurship indicates a way of acting freely in an economic game and in society as a whole. In a neoliberal governmental rationality, human beings are conceived as autonomous entrepreneurs of their respective lives: life is regarded as an enterprise, qualified in terms of choice, investment, competencies, and (human) capital, and oriented by highly diverse needs.

It is important to note that neoliberalism is much more than a strictly economic theory. Neoliberalism serves as a framework with which to analyze functioning in noneconomic domains, that is, “to remove a little of the mystery from the economic and social world that we live in” (Becker 1993, 25). Neoliberal government does not of course *give up* “the social” as a governmental concern; however, a significant transformation occurs. Social relations are now regarded as the outcome of enterprising activities of individuals; these relations exist, furthermore, as long as they constitute a worthy investment and suit the needs of the given individuals. Notice that a totality of enterprising selves with diverse needs is not the same thing as the society that had been conceived in a normative sense in the earlier period. Indeed, a community is no longer regarded as a natural (or, national) state of people among whom there is, by nature, something shared in common. A community is instead a temporal collection of people who have something in common because they have chosen the same, because they have an agreement or a contract.

From a governmental perspective, individuals are required who have the ability to participate and communicate, that is, individuals who have the ability to participate in those kind of communities that represent clearly and transparently what is important for them, and who have the communicative skills to formulate a common goal and reach a consensus. Within this configuration, relations among people are increasingly conceived as contracts, which arrange the complex of duties and responsibilities between people. Moreover, the relation between individuals and social institutions is con-

ceived in a different way. Public services (such as schools) become enterprises with clients whose needs those services try to meet. Again, the point of departure of this governmental configuration is the enterprising self, who autonomously chooses services that will meet her needs. In short, these enterprises themselves demand certain abilities to participate and communicate in certain ways.

Within this governmental configuration, exclusion is defined in a new way, or more precisely, inclusion becomes a permanent target of government. Exclusion consists in the lack of opportunity to participate and to live one's life as an autonomous enterprise. Inclusion—the remedy for exclusion—is no longer seen as the integration of everyone into society in order that each one may have a normalized social identity. Rather, inclusion is now believed to consist in the opportunity for one to obtain those skills of participation and communication that are required in order to operate in the community of entrepreneurs; that one is able to choose or construct an identity, to invest in oneself and others, to choose what is fitting to one's own individual needs. What has become important is not participation and integration in normal and normative society; what is important is the capacity to participate and integrate *as such*. In other words, participation and communication, as well as other “functional” skills, become essential for actual governmentality, whose motto might be, “Do whatever you want, but communicate, participate, invest, express your needs, and choose.” For this community, there is no outside; furthermore, that certain people have “mental or physical handicaps”—in the traditional sense—is not a reason to exclude them because they, like others, have their own needs, and each of their lives can include enterprise as much as can the respective lives of nonhandicapped people. The problems that disabled people confront are not different in nature, but in degree; furthermore, insofar as living a life as an entrepreneur is to have needs and to be able to solve problems, a distinction in the population of pupils is (from an educational perspective) unnecessary.

Given the remarks that have been introduced to this point, we can now argue that the discourse on inclusion—with its concepts of “inclusive schools” and “inclusive society”—is an effect of government, and an instrument of government from the view of the community of entrepreneurs. Let us take a closer look at this discourse.<sup>2</sup>

### *The Discourse on Inclusion*



During the 1980s and 1990s, segregation in education is put into question by the so-called inclusive schools movement, or inclusionists. For members



of this movement, at least in its radical form, the issue is no longer integration and mainstreaming, or how to legitimate a kind of gentle exclusion (cf. Fuchs and Fuchs 1994, 299ff.). As the notion of “inclusion” suggests, the issue is how to include all pupils in education, taking for granted that segregation is something that does not belong to modern democracies, that is, inclusive societies. As Thomas states, “The recent popularity of inclusion as an idea in education probably rests at least in part on its consonance with this wider notion of inclusivity in society: i.e., of a society in which each member has a stake”; Thomas continues, furthermore, by claiming that “aggressively meritocratic, individualistic and competitive thought . . . provides ample rhetorical justification for segregation. By contrast, in a different outlook, which regards all members of society as stakeholders, it is natural to see schools as places where all are welcome” (1997, 104–5).

What Thomas describes as a “society of stakeholders” reflects well the concept of the community of entrepreneurs as a correlate of government. In this community of entrepreneurs, cognitive or physical disability is not a reason for not having a stake. The question, therefore, is how to think about education from a governmental perspective, which has this inclusive society as its correlate. In the words of Gartner and Lipsky: “How then does one shape an educational system to include students with disabilities, one which is both consonant with and builds toward an inclusive society?” (1987, 387). As these authors note, the alternative to separate systems is a merged or unitary system. They point out, however, that the conception of a unitary system requires a “paradigm shift”; that is, a unitary system requires a fundamental change in the way that we think about differences among people, in how we choose to organize schools in order to educate people, and in how we conceive the purpose of that education (1987, 388). Referring to Kuhn (1996), these (and other) authors claim that inclusion involves a changed paradigm in which to think about education and differences among people. Inclusion is presented as a new way to think about education and society, where the necessity to segregate, and especially the distinction between normal and abnormal pupils, is banned.

To be sure, we agree that there has been a general transformation in thinking about education; from the perspective of governmentality, however, it is crucial to consider this transformation in educational practice in relation to changes in thinking about individuality and society, in general, and in relation to the underlying continuity of the double bond of individualization and totalization, in particular.

The inclusionists argue that special education has to be abolished; in addition, they argue that regular education itself needs to be radically trans-

formed in order to ensure that it can attend to the needs of all children. Inclusionists do not merely want to abolish special education and “dump” pupils in regular schools; to the contrary, they want to transform regular education, and even society itself (Gartner and Lipsky 1987, 386). As Stainback and Stainback claim, “The designation of arbitrary cutoffs does not make students any more different between the special and the regular groups than within these groups. . . . In short, there are not—as implied by a dual system—two distinctly different types of students, that is, those who are special and those who are regular. Rather, all students are unique individuals, each with his/her own set of physical, intellectual, and psychological characteristics” (Stainback and Stainback 1984, 103). The point of departure for education is the “uniqueness of individuals,” and how to take into account the educational needs related to this uniqueness.

Thus, this discourse on inclusion in education could be summarized in the following formula: “Good education for all.” In this context, the term “all” does not refer to a population divided into categories of “normal” and “abnormal” pupils who have “normal” and “special learning needs,” respectively; instead, the term refers to a population, or totality of individuals, each of whom has specific and unique needs. As Wedell puts it: “If an education system is geared to meeting the diversity of pupils’ learning needs, the inclusion of pupils with SENs (special educational needs) becomes just one part of this diversity, and so does not have to be separately justified” (Wedell 1995, 101). “Good education” could be understood as “effective instruction,” where appropriate educational supports would include (for instance) assessment based on multidimensional axes, psychosocial evaluation directed toward instruction, instructional practices that utilize current research, classrooms and schools designed to incorporate effective schools research, enhanced staff and curriculum development, early intervention and transition programs, postsecondary education, training, work, community-living options, and so on (Gartner and Lipsky 1987, 388). As Gartner and Lipsky explain, “A new system means curriculum adaptations and individualized educational strategies that would allow both general and special education students to take more difficult courses” (388). For the inclusionists, the starting point of the shift is clearly the “acceptance of pupils’ diversity,” and a reformed educational setting that is able to meet—through effective instruction and without segregation—the diversity of needs that this diversity of the pupil population implies (Wedell 1995, 101). The following remark by Glaser, although not discussing the relation between special and regular education per se, expresses well this transformation in discourses on education.

Instead of attempting to fit students into a monolithic, relatively uniform program, educational institutions must be designed to be adapted and flexible enough to fit diverse students. Quality and equality in education consist not in offering the same program to all, but in maximizing the match between individual abilities and the environments in which teaching and learning take place. (1977, 5)

To put it more emphatically, the “school” is no longer a normal and social institution in the traditional (that is, modern governmental) sense of the word; instead, the “school” has become a flexible enterprise that must meet the diverse needs of individual pupils. In this context, and looked at from the perspective of governmentality, we should underscore that this individual with needs and entrepreneurial freedom is not one who “naturally” appears when segregation and normalization are resolved and inclusive education is established. To the contrary, the “individual” of the discourse on inclusion is *an effect*, or *product of* that discourse and the neoliberal forms of governmentality with which it correlates.

As noted above, the radical inclusionists defend “good education for all,” as do the proponents of segregated education and integration/mainstreaming. The differences between the approach of the radical inclusionists and the approaches of the latter stem from a major shift in what is understood by the terms *good* and *all*. The point of departure for the latter (proponents of segregated education and integration/mainstreaming) is the mainstream and normal school (where “the normal” is normative and hence representative of what is “good”) and, as its necessary consequence, the legitimized exclusion of disabled pupils or pupils with special educational needs. To put it more directly, according to this view, pupils in regular schools do not have “needs” in the strict sense, because the normal school and regular teaching meet their “needs.” The basic assumption of the inclusionists, however, is that “all” means the totality of different individuals (each of whom has differing educational needs) and that good education occurs in an adapted and inclusive educational setting that takes into account the needs of each and all. Furthermore, diversity is not just the basic condition for instruction; rather, diversity is presented as a basic feature of an inclusive society—a society in which each individual has a stake. “Society” no longer refers to a substantive collectivity; instead, “society” refers to a collection of temporary organizational structures that meet the needs of individuals, construed as a community of entrepreneurs. Clearly, within this changed governmental space, with its correlate of a “community of entrepreneurs,” “education” is transformed. For neoliberal governmen-

tality, “education” is the collection of particular schools, which function as enterprises and attempt to offer quality for all (see Simons 2001).

It could be argued that the governmentalization of the school is coming to an end as education adapts itself to the differences among people. Indeed, it seems as if the double bind of individualization and totalization, a feature of modern governmentality, has broken down. We believe, however, that this is not the case, although we certainly agree that there have been important transformations.

The framework of education, at least for primary and secondary schools, remains the nation-state. During the 1970s and 1980s, in different countries, “national” curricula have been formulated according to what is necessary in order to function in “society,” where this object is construed as a totality of individuals who enhance individual well-being and freedom, as well as national well-being, through their entrepreneurial behavior. To function in society is to have the basic (social) skills to govern one’s life as an enterprise. The term *national* in the phrase “national curricula” no longer refers to a common good (say, knowledge or morality); rather, the term implies formal abilities that are necessary for each and all in order to behave as an entrepreneurial self. National curricula is about knowing the rules needed to play the game, having the skills to participate and communicate in the process of arriving at a consensus or a contract, and being able to problem-solve. In fact, what the game and communication is about—the content of the consensus or the contract—is related to one’s own preferences and choices. To put it in another way, all individuals are regarded as different, however, what they have in common—or should have in common—are those skills and abilities to live their own lives (to participate, to communicate, to “learn”). These skills are important, and maintain a governmentalization of the school and the modern process of individualization and totalization within the “nation”-state.<sup>3</sup> In short, although our understanding of “individuality” and “totality” has changed, actual government still acts upon a totality of individuals who all exercise freedom *in the same way*.

### *Beyond Inclusion and Exclusion*



As we have indicated, a main feature of modern governmentality is the double bind that exists between individualization and totalization—that is, human beings become subjects by exercising freedom according to certain rules, virtues, norms, or skills, which they share with other free subjects. As

we have pointed out, furthermore, this freedom and government have histories (as does this double bind), histories that extend from norms of (civil) society, to the social individual, through the skills of an inclusive society, to the entrepreneurial individual. Modern education plays an important role in the (re)production of this double bind. For modern government and education, human beings are simultaneously regarded as individuals and members of a totality. In other words, they have something in common, they share something or, at least, they have the skills to negotiate and communicate in order to arrive at a consensus or an agreement. In a general sense, the notion of community that underlies modern government understands “community” as relations between individuals who have something in common. Throughout modern government, and up to this time, human beings have been considered able to know, to formulate, and to define what this “common” entails, that is, what community is about, what the members of the community share (or should share).

Here, then, it becomes clear how the notions of exclusion and inclusion link up with modern government and its underlying notion of community. It is with regard to such a community, defined through what people share or to what they belong, that the discourses on exclusion and inclusion receive their meaning. The recent discourses on inclusion seem to put an end to a narrow definition of community and individuality and, hence, to any kind of exclusion. The slogans “education for all” and “a society in which all have a stake” reject all of the narrow definitions of inclusion (and, thus, reject the exclusion of the large number of people who were previously excluded). As the notion “inclusion” suggests, however, inclusionists hold to the principle of defining what people have—or should have—in common: communicative skills, enterprising capacities, and the ability to define and agree upon a common good. From this perspective, recent discourses on inclusion repeat the double bind of individualization and totalization, processes that are a major concern for Foucault.

At this point in our argument, we would like to problematize the notion of community in order to criticize this double bind. As we have indicated, from a governmental perspective, a “community” is regarded as a totality of people who have something in common (cf. Rancière 1998, 83ff.). This definition of a community (including the ability to define what “the common” is, or to participate in the process of that definition) must be questioned. As Esposito argues, the assumption upon which this conception of community relies is that individuals have something in common, which at the same time allows each of them to be a unique individual (2000, 16); for example, insofar as one shares a communicative competence with others,

one is able to express one's own most individual aspirations. For the common is regarded as a kind of property of the subject, or one of its qualities; a community, furthermore, is seen as comprised of people who are united by this common property.

As Esposito points out, however, the original meaning of *munus* in *communus* (void, debt, gift) is exactly the opposite of this conception. According to him, a community is not about having something in common, something that we share with others, but rather about the opposite; that is, community is not about having, but rather, about lacking; not about "something," but rather, about "nothing." This void or lack refers to what we owe to others; in addition, this void or lack means that we have obligations toward others, despite the fact that we are not able to define precisely what these obligations are. The "I" or "you" is caught up in a network of obligations that it cannot master. The subjects of a community are united by a task in the sense of "I owe you something" (not "you owe me something") (Esposito 2000, 20). Being united by a task or obligation means precisely that there is a void, or nonrelation, between subjects, between me and the other. Living together or living with others in a community is not about living with those with whom we share something; rather, living together means that we have obligations and responsibilities that go beyond individual subjectivity and its properties. Even more, the experience of these obligations toward the other is exactly a sign that my subjectivity, just like my relation toward others, is not completely transparent for my consciousness. As Readings states, the network of obligations "is not entirely available to the subjective consciousness of an individual so that we can never pay all our debts. Indeed, the assumption that we can pay all our debts is fundamentally unethical, since it presumes the possibility of overcoming all responsibilities and obligations, achieving 'freedom' from them" (1996, 186). The experience of obligations involves the experience of the other in myself that I cannot take into account, or a passivity that is part of my activity as a subject. The very notion of community includes an infringement of subjectivity. Assuming this point of view, Esposito (and others) holds that a main feature of modernity is a continuous "immunization," that is, a filling of the void between people and protecting them from a possible shred of their subjectivity. Immunization, therefore, involves defining what we have in common and what we owe to each other, transforming every social relation into a transparent rule, norm, contract or agreement, and regarding every task as an (economical, calculable) exchange. Immunization is not only about transforming human subjects into closed individuals whose social relations are arranged by common

juridical, moral or political rules; immunization is in addition a shield against the passivity and void within the subject.

Without discussing this in detail, it is possible for us to draw a parallel between the concept of immunization and Foucault's idea about the double bind of individualization and totalization. Modern government of *omnes et singulatim* (all and each) presupposes a specific conception of community—as sharing something or having something in common—and a related specific conception of human subjectivity—a closed, self-grounding subject or individual (Foucault 1981). To put it another way, modern government acts upon an immune totality of individuals or subjects with an immunized relation to the self and to others. In its actual form, this immunization becomes most clear in the transformation of social relations into contracts, the insistence on agreement and consensus in communication, the necessity of accountability, and the view that human beings, as autonomous entrepreneurs, have the ability to express their needs and to solve problems (“to learn”). As we have pointed out, a confrontation with this immunization is expressed in terms of exclusion and inclusion: exclusion for not sharing or having in common, and a further inclusion, that is, sharing something or at least having the ability to share something. The discourse on inclusion is not, therefore, critical about, and actually advances, the process of a further immunization of human beings and their relations, as well as the double bind of individualization and totalization. This elaboration of the Foucauldian double bind with the notion of immunization helps us to go beyond a modern concept of community and beyond the problem of disability construed in terms of exclusion and inclusion: a relation of responsibility toward the other, without foregoing immunization, that is, transforming the other (and myself) into a normal, competent, or enterprising individual.

### *Conclusion*



As pointed out above, the discourse on inclusion, although it focuses on the needs of every individual, assumes that all human beings have something in common; therefore, within the terms of the discourse on inclusion, no kind of exclusion is tolerated. In Foucauldian terms, however, an inclusive society seems to be one in which the double bind of individualization and totalization is realized. One might argue, furthermore, that within this “society without an outside,” and within inclusive education in particular, every human being is regarded as exclusive, since what is taken in account is

every individual need. The “unique individual” and the appearance of its own (educational) needs cannot, however, be regarded as the so-called true nature of human beings. Rather, as we have pointed out, this idea of human uniqueness is both *effect of* and *instrument of* discursive and governmental practices. In other words, what the discourse on inclusion takes for granted—namely, that human beings become individuals by belonging to a totality—is part of a governmental history and, furthermore, exemplifies the double bind of individualization and totalization. In addition, as Esposito has enabled us to show, a totality of individuals who exercise freedom in the same way as each other are human beings with an immunized relation to the self and to others: they know what they are, what the others are, and foremost it is clear to them what they owe to each other. We agree with Readings, therefore, that “the opposition of inclusion to exclusion (even a total inclusion of all humanity over and against the space alien) should not structure our notion of community” (1996, 187). Here, then, we would like to return to Skrtic, who concludes his discussion with this claim:

Successful schools in the twenty-first century will be those that produce cultivated citizens—liberally educated young people who can live and work responsibly and interdependently under conditions of uncertainty. The curriculum and pedagogy in these schools will promote students’ sense of social responsibility, awareness of interdependence, and appreciation of uncertainty by cultivating their capacity for experiential learning through collaborative problem solving and reflective discourse within a democratic community of interests. (1995, 259)

We do not intend to discuss this analysis in detail; rather, the question that we wish to pose is this: to what extent does Skrtic—who claims that it becomes possible to “actualize the adhocratic values of inclusion”—still regard schooling as a main instrument in the process of immunization? The starting point for an adhocratic school is the permanent condition of uncertainty; in the adhocratic school, furthermore, learning is about collaborative problem-solving within a community of interests. Therefore, the ongoing process of learning and collaborative problem-solving seems to be the ongoing process of immunization itself, insofar as it is an ongoing struggle with the permanent condition of uncertainty. Because the point of departure for the adhocratic school is a community of interests, this transformation of a community into a community of interests could be understood as a further step in the process of immunization. Our argument, furthermore, is that the notion of a “community of interests” seems to rely



upon the assumption that we could “pay all our debts.” This assumption must be questioned, for it implies that we know what is (or, what should be) binding us. In other words, the notion of a community of interests amounts to a refusal to accept our responsibility or obligation toward one another. When democracy is construed as “collaborative problem-solving through reflective discourse within a community of interests” (Skrtic 1995, 259), the extent to which the double bind of individualization and totalization (or, the process of immunization) characterizes the political regime of democracy becomes more evident. According to Skrtic, progressive education, the adhoc school, and collaborative problem-solving could “save democracy from bureaucracy” and education from professionalization. Our concern, however, is to save democracy and education from an ongoing immunization.

#### NOTES

We thank Shelley Tremain for her help with the translation of this chapter.

1. Within the scope of this chapter it is not possible to deal with these topics and problems in detail. Our main purpose is to show how Foucault’s concept of governmentality enables us to understand the actual insistence on “inclusion” and to explore to the extent to which it makes sense to think in terms of “exclusion and inclusion.” This exploration is part of a broader research project that deals with actual discourse on the learning society and quality assurance in education (Masschelein 2001; Simons 2001).

2. Of course, there are different positions within the “inclusive school movement.” Since our goal is to argue that the increasing interest in inclusion is related to transformations in governmental relations, we do not intend to discuss these differences in detail.

3. We cannot develop this point here; it is clear, however, that the idea of “nation” is not simply disappearing, regardless of references to the “United Nations,” or even the “European Community” and the “global society.” What is at stake according to us is a certain thinking of community that we criticize in the following sections of this chapter.

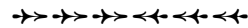
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CHRIS DRINKWATER



## Supported Living and the Production of Individuals

### *Our Institutional “Other”*



It is official. Long-stay residential institutions for people with learning disabilities are bad.<sup>1</sup> Supported living in the community is good. The U.K. Government white paper *Valuing People* projected that by the year 2004 nearly every person with a learning disability shall be living in an ordinary house, on an ordinary street, receiving just the amount and kind of care or support that is needed to enable the individual to live a valued life (Department of Health 2001, 6).

What does it mean, this shift in public policy from segregation toward normal living, from exclusion to inclusion? One answer might be that the change is the outcome of a great reform, a long-overdue recognition of people with disabilities as people “like ourselves,” *people* first and foremost, with feelings, individual differences, abilities, dreams, and life stories.<sup>2</sup> Each person is unique and wonderful. How could public services have, for so long and so egregiously, ignored this fact? We see black-and-white images of the old hospitals, hear the stories of misery and worse, the cruelty, the daily ritualistic torture, the sporadic coming to light of violent abuse, and we breathe deeply in the knowledge and relief that we are living in better times. It seems barely possible that until so recently people were segregated in this way, made vulnerable to abuse, as a matter of public policy, rather than as the occasional and regrettable exception to a humanitarian rule.

I want to suggest, in the spirit of Foucault, that supported-living arrangements exemplify not an emancipation, nor even a humanitarian reform, as much as a new dispersal of power relations, one that is entirely in keeping with the modern drive to greater efficiency. Perhaps the “care in the community” of large numbers of people, who have been, or would have been, incarcerated, has been made possible only by an intensification and multi-

plication of power in society at large, in the “social body.” The new policies of inclusion represent a momentous shift, nonetheless. For, as Foucault has shown, “we” normals have constituted ourselves through the exclusion of others, criminals, mad people, disabled people (1988, 146). Now, however, the residential institution itself is othered. We define ourselves in opposition to such dark practices as the long-stay hospital symbolizes. Now that practices of exclusion are officially challenged and delegitimated, we might, then, ask: What new forms of power are at play in the new practices of inclusive living?

### *Power and Individuality*



In Foucault’s materialistic analytics of power, meanings, values, persons, and things all emerge in, from, and through networks of relations. How are these relations to be described? In the work of his “middle” and “late” periods, through the 1970s until his death in 1984, Foucault depicts the emergence since the eighteenth century of a distinctively modern kind of power. Rather than sovereign power, which is top-down, juridical, and fundamentally negative, insofar as it is a power of life and death—a power, that is, to deduct and seize—modern power is ubiquitous and possesses no center (in the form of monarch or state). Modern power regulates from the bottom upward; it distributes practices around a norm, in highly specific and localized ways. It is positive and productive—power over life rather than power of death.

[Deduction now is] merely one element among others, working to incite, reinforce, control, monitor, optimize and reinforce the forces under it: a power bent on generating forces, making them grow, and ordering them, rather than one dedicated to impeding them, making them submit, or destroying them. (Foucault 1979, 136)

Power now exerts a positive influence. The business of modern power is “the administration of bodies and the calculated management of life.” Its main role is “to ensure, sustain and multiply life, to put that life in order.” Modern power invests life through and through (Foucault 1979, 138–40). On the macrolevel, power now controls populations, the “body politic.” On the microlevel, it subjugates bodies in positive, productive ways. The emergent biopower “brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life” (143). The task of the critical analyst is to describe these

new technologies of power, to describe “the techniques, the practices, which give a concrete form to this new political rationality and to a new kind of relationship between the social entity and the individual” (Foucault 1988, 153).

In some late, brief articles, interviews, and lectures, Foucault refines this conception of modern power, distinguishing it ever more sharply from constraint and violence. Power, he points out, is

a mode of action which does not act directly or immediately on others. Instead it acts upon their actions: an action upon an action, on existing actions or on those which may arise in the present or the future. (1982, 220)

Power thus structures the field of possible actions. Playing on the double meaning of the French verb *conduire* (to lead or to drive) and *se conduire* (to behave or conduct oneself), Foucault says that power *conducts*, both in the sense of leading / guiding, and of “behaving within a more or less open field of possibilities” (Foucault 1982, 221).<sup>3</sup> Drawing upon early modern usages of “government” and “police,” and his own notion of modern secular “pastoral” power, Foucault traces the development of forms of power that are “the specific techniques by which a government in the framework of the state was able to govern people as individuals significantly useful for the world” (1988, 154). The very happiness of individuals becomes a matter for the state, a condition of its survival and development. The police *take care of* individuals. They govern “not by the law, but by a permanent and a positive intervention in the behavior of individuals” (159). Foucault’s later genealogy of modern power sharpens a distinction that he had already drawn in earlier texts, a distinction between power, on the one hand, and confrontation, violence, and slavery, on the other. Power may relinquish its role to these devices when other means fail; however, freedom of the subject is a precondition and a “permanent provocation” (Foucault 1982, 221) for power. Agonism marks the relationship—perpetual struggle, mobility, and the persistent possibility of transformation and transgression.

### *Power Relations in Supported Living*



### *Inclusion as a Form of Production*

The name of Foucault is often associated with the analysis of the *total* institution—the prison, the asylum. In an important clarification, however,

Foucault advocates the analysis of institutions *from the standpoint of* power relations, not vice versa (1982, 222). This shift is, of course, vital to an account of the power relations that emerge in supported housing. When explaining these relations, there is a tendency to seek institutional remnants, such as behaviors of both staff and service users that have been learned within institutional environments. But this tendency precludes the analysis of new forms of power at work, new types of relation, different kinds of actions upon actions, different techniques for inciting desired behaviors.

In fact, the supported household offers a purer form of power than the institution, a form of power that is not dependent upon exclusion, one that is more distant from constraint. Well-publicized instances of institutional violence may indeed have hastened the state's movement toward community-based services. We may, therefore, analyze social inclusion as a strategy of power, the objective of which is the making of good citizens. Once the context of the supported household is recognized as one that is embroiled in power relations, the productive aspects of power that are fundamental to that arrangement become even more evident than those aspects were in the context of the institution. For modern power, as the administration of life, was always *fundamentally* inclusive. Administrative rationality, *not* humanitarian reason, is that which has actually led to the end of the death penalty in most Western countries. We might, therefore, say that the inclusion of formerly excluded people by means of community-based services is a continuation of the logic of modern power—power over life. The supported household offers total life management, a dream of the modern state. The *policy* of community-based care may be regarded as a large-scale reorganization of the body politic, biopower at the macrolevel, the level of populations. For modern government is concerned with the well-being and well ordering of the population as a whole; the social body and the individual body, furthermore, form its matrices.

### *Founding Knowledges and the Exorbitance of Values*

The most prominent technology informing practices of community-based support is “social role valorization” (SRV), so named by its architect, Wolf Wolfensberger, in order to stress the *normativity* of “normalization,” as it was previously called (Wolfensberger 1991; Flynn and LeMay 1999). SRV uses “socially valued means” in order to bring about valued lifestyles for people who have been traditionally devalued. In addition, SRV must promote valued *behaviors* in its subjects, since other people in the community

will only value these subjects if they behave in valued ways. Actions to bring about valued individuals are set within complex, mobile fields of power/knowledge. As Mike Oliver (1994, n.p.) puts it, “Normalization theory offers disabled people the opportunity to be given valued social roles in an unequal society which values some roles more than others.” Indeed, changing the name of normalization theory to social role valorization actually leaves in place the power/knowledge regime that is productive of “a normal life” (by any name). Aspirations, dreams, plans are reduced to the desire to be assimilated into the social body, and to the implementation of this desire. Behaviors that resist this goal are *problematized*; that is, these behaviors are endlessly discussed, interpreted, and made into the objects of tactics and strategies, as raw material that must be molded and changed. The assumption underlying these “actions upon actions” is that certain people (in the United Kingdom, “people with learning disabilities”) have difficulty in learning to behave “appropriately”; furthermore, these difficulties can, with support, be overcome. A more tacit assumption<sup>4</sup> is that the person with a disability *should* learn normal (valued) behaviors in order to acquire normal (valued) lifestyles. For valued behaviors can be learned. To have a learning disability is, then, to find it difficult to perform valued behaviors. SRV enables the support team of a household to enhance such learning, to enable individuals to change their behaviors. The consequence (reward) is to enter the virtuous circle of valued behaviors leading to valued responses, which results in enhanced self-esteem, which in turn encourages more valued behaviors. In short, SRV is a value-adding machine.

In particularly problematical cases (such as when members of a support team encounter “challenging behavior” from an individual who resides in the house in which they work), the services of a worker with specialized knowledge may be summoned. That is, the clinical psychologist may be consulted. More often, the support team employs crude modification techniques, without having sought specialized advice. In all such instances, consistency is impressed upon every member of the support team. Like actions are called upon to produce like desired responses. Valued behaviors are commended; nonvalued behaviors, if not exactly punished, must be seen by the service user to be associated with undesired outcomes. At the least, service users must be made aware that their actions produce *consequences*. This is what it is to learn the meaning of responsibility.

The principles of normalization, or social role valorization, are enshrined in *Valuing People*, a document that has been widely acclaimed by organizations of and for people with learning disabilities in the United



Kingdom. For what can be objectionable in “providing people with learning disabilities with new opportunities to lead full and purposeful lives,” or supporting people in “developing their capacity to do what they want,” or helping people to “develop social skills and the capacity to form friendships and relationships with a wider range of people,” or enabling people “to develop skills and enhance their employability” (Department of Health 2001, 84)?

The esteemed values of rights, independence, choice, and inclusion obscure the actual lived relations of support/power. These ideals provide no hint of the conflict between power and freedom, responsibilities and rights, choice and what are called “developing capacities.” The discourse enshrined in *Valuing People* leaves no space for critical thinking about the actual operations of support, the techniques of normative induction, the persistent “action upon actions” that constitutes the reality of power in the everyday. This discourse is unable to problematize “the way in which knowledge circulates and functions, its relations to power. In short, the *régime du savoir*” (Foucault 1982, 212). It is as if values cancel out power. “We” employees of the service agencies are exhorted to think constantly about values, rarely about power, never about power relations between service users and support workers—*except* where service users are deemed to behave in a “manipulative” fashion, in which case *they* are seen to attempt power play over *us*. The discourse of valuing does not permit an analysis of “manipulation” as a form of resistance: the resort of the valued subject who simply wishes to make a less than fully valued choice. Whose truth? we may ask. Relations in supported housing continually beg the question. The service user must learn to exercise freedom with responsibility. Support workers understand the concepts and associated practices more clearly than service users, it is assumed. Cultural values must be reinforced.

Perhaps it is in the very moment of valuing “the person” (the instance of greatest ethical commitment) that support services exert their greatest subjectifying force, the end of which is the production of a citizen well integrated into the given constitutional framework—of rights, responsibilities, and equal opportunities.<sup>5</sup>

### *The System of Differentiation*

One aspect of analysis of power relations is attention to the system of differentiation (Foucault 1982, 223). Which systematic differences does the supported household instantiate? Support workers are paid, service users are not. Support workers are “staff.” Staff are expected by their employer—the

agency—to bring certain pressures to bear, allow certain actions, and discourage or actively prevent others. Service users are free to choose between a range of options. Staff come and go. One finishes a shift and is relieved by another. The staff member fulfills a role. That individual is a team member. Staff communicate information, about service users, to other members of the team. They write in the service users' personal diaries and communication book and fill in incident reports.<sup>6</sup> They discuss matters in supervision sessions and team meetings, discuss service users and the means of government, the structuring of the field of possible actions. Discussions like these serve to determine what service users are and what they may become.

Staff possess certain competences, which are not shared by service users. Staff are *able*. This basic differential assumption is tacit, hardly spoken. Indeed, the term *able* might never be used in this context. And yet, it is a fundamental assumption of the service that staff are more able than service users, and thus are able to guide them.

Staff function within a hierarchy, an organization to which the service user relates, but of which that individual is not a part.

### *The Production of Self-Regulating Subjects*

Foucault endorses us to ask of power: *how* is it exercised? Power is not a thing, to be scrutinized, of which one might ask, “*What* is it?” nor even, “*Why* is it thus?” Power is a type of relation in which one person or group of people *acts upon the existing or possible future actions* of another person or group of people (Foucault 1982, 220). How do workers in supported-housing environments act upon the existing and possible future actions of service users so as to limit the range of acceptable actions and delineate the outlines of a certain individuality? A range of tactics is employed: the inculcation of bodily disciplines, surveillance, and more or less persuasive techniques for eliciting compliance. The latter are structured according to what may be understood as the principle bargain: that a valued social role will only ensue from valued behaviors.

*Regimen of the Body* The daily practice of supported living revolves around the body of the service user: habits, behavior, conduct, hygiene. Strongly encouraged habits include getting out of bed in the morning, bathing and all other aspects of personal hygiene, shaving (for men), dressing well, going out and doing things. Complex movements such as crossing the road safely and eating behaviors must be learned. These rituals seem so necessary, so obvious, it is difficult to view them critically. This is the dan-

ger to which Foucault alerts us. The given is always historical, always a complex production of power and knowledge. Where are the “limits of the necessary” in these practices? Which limits contribute to the autonomy of the individuals concerned? Which limits are arbitrary or serve only heteronymous ends?

Sexual discipline is a prime component of the regulation of the body. Williams and Nind (1999) argue that the ideology of normalization has served to control the sexuality of women with learning difficulties. Striving to be valued, women with learning difficulties learn to police themselves (668). Williams and Nind conclude: “Perhaps real empowerment of women with learning difficulties will . . . come to show how normalisation has acted as a silencing of voices” (669).

Again, modern power consists in the “administration of bodies and the calculated management of life” (Foucault 1979, 140). It is concerned with life, hygiene, and health. It gives meaning and value to bodies (152). Because supported-housing offers a benign regime in comparison with the total institution, it may not be easy to see that it administers bodies and manages life.

*Surveillance* Foucault (1977) identifies the Panopticon, a prison designed to induce a state of constant visibility, as the archetype of surveillance. For prisoners’ cells are arranged in a ring around a central observation tower, from which prisoners can be seen at any time. The prisoners cannot, however, see into the tower, nor are they able to see or communicate with one another; thus, they can never be certain whether or not they are being watched, nor even whether, at any given moment, there is someone in the tower who could watch them. The prisoners learn to *behave as if* they are under observation. The presence of the guard is not necessary; for it remains a perpetual possibility. In short, the prisoner, who must learn to keep watch over himself, is compelled to adopt the role of the prison guard.

What has the Panopticon to do with supported housing in the community? No special architectural arrangement exists in the community, no placing of bodies in order that they can be seen and cannot see. Service users have keys to their own bedroom doors. How can an ordinary house, on an ordinary street, be said to reproduce something like the function of an ideal prison?

It is true that service users are not placed under continuous observation—but then, neither was the prisoner. The tower is not a necessary instrument. In supported housing, the tower’s place is taken by the personal diary, in which any observed behaviors *may be* (or may not be) recorded for the eyes of other members of the support team and those of more senior

rank in the organization. It is a fitting irony that this most private of “windows upon the soul” (namely, the personal diary) should, in the supported-living environment, have become a principle instrument of power/knowledge, maintained and administered by the service agent, and containing all manner of information about the service user. *The book*, as it is called, is a frequent object of reference by service users. The question, “Are you going to write it in the book?” often relates to actions that the service user wishes other staff to know about, behaviors for which they anticipate approval. Sometimes service users watch over support workers while they record observations. By contrast, when service users have committed misdemeanors, the knowledge of their recording is encountered with resignation, or pain, or hostility. Support workers are of course perfectly reasonable in their explanation of why “the book” must be used: members of the team need to share knowledge in order to be able to support service users effectively. The first task of a team member coming on duty is to read the communication book for messages; the second task is to read the personal diaries of service users. Support workers pick up on cues, play a consistent part in processes of reinforcement or discouragement, and carry on what has been started.

Over time, through working directly with service users, in addition to reading the diaries and other records and discussing their contents with other team members, support workers build up a picture of the service user, a more or less clear image of the individuality of a person. They learn to act together, to support desired behaviors, to discourage undesired behaviors, and to develop strategies for change. For their part, service users learn that *there are no secrets*. Service users know that each member of the supporting team holds the knowledge of all. If service users learn anything, it is to be *on guard*. As the purpose of the Panopticon is achieved when each prisoner becomes his own guard, so too the support function is realized when service users behave *as if* they are being observed, by monitoring their own activities.

*Eliciting Compliance* Support workers must act upon the actions of service users, to limit the existing and possible range of actions. Support workers have limited means at their disposal with which to do so. One, the diary, has been described. In general, workers depend upon the maximum enhancement of ordinary techniques of persuasion. One of the key uses of the diary is that it enables workers to act as a team, responding in like manner to like behaviors, working together to produce valued behaviors. What is the aim of these techniques? It is to produce valued subjects. Foucault

(1982, 212) draws attention to two senses of the word *subject*: subject to someone else by control and dependence, and subject to oneself by conscience or self-knowledge. Supported living, it might be said, aims for the transformation of the first mode of subjection into the second, that is, for the transformation of “subjection” into “subjectification.” The process is fraught. Subjectification cultivates sweet reasonableness in the service user. Often, this doesn’t work. If reason fails, then rules must follow, which can only appear arbitrary to the unreasonable subject. Power meets resistance. Processes of subjectification are fields of struggle, self against self, self against others, and others against self. The question at the heart of the struggle is, “Who or what shall determine the identity—the subjectivity—of this subject?” It seems obvious that supported living in the community, at its best, strives for the autonomy of the individual subject. Choice, respect, recognition of rights, access, community presence, and all the heralded principles of community living aim toward autonomy (O’Brien and Lyle O’Brien 1990). Yet even at its most enlightened, the supportive relation is immersed in power, and its essence is to induce people to act normatively *of their own free will*. Support workers are officials of pastoral power, guiding service users on the road to salvation, understood, in a revised modern sense, as an ordinary life of sufficient well-being. To support is to lead others into the right. It is to craft citizens, reasonable subjects of the democratic state.

*The Bargain/Condition: A Valued Social Role Requires Valued Behaviors* “The adjustment of abilities” (Foucault 1982, 218) nicely describes the role of pastoral power as it is exercised by the support worker. Service users’ behaviors are acted upon in such a way that they become valued. Service agents and service users are collaborators in a labor process that produces valued subjects on the basis of knowledge of what is valued. In producing valued subjects, the process not only modifies behaviors, it constitutes a certain *experience* of being valued, as the service user learns to identify with a set of hypothetically common aspirations (values).<sup>7</sup> Service users become agents in the system, collaborators in the forming of valued lifestyles. In so doing, they learn what it is to be “constitutionally competent,” developing a “shared commitment to shared practices” (Law 1999, 9). They learn which kinds of choices they need to make if they are to be recognized as valued persons. They learn to be *responsible*, in the sense that they understand that actions have consequences, not the least significant of which are the approval or disapproval of their support workers.

### *Disciplining Workers*

Service workers are not only actors in games of power. Like the Panopticon guards (themselves objects of surveillance), service workers are acted upon in ways that make them more efficient and more able agents of government. Service workers have already been “subjected,” through families, education, and previous employment. As already well-functioning individuals, they are able to perform as role models. (In cases where the normalization of individual workers has been less effective, they are likely to be under suspicion and pressure.) Beyond this necessary background, work disciplines harness and tune their competencies. The service user’s personal diary has already been cited as a key technology for surveillance and disciplining of the service user. This, and other, records also ensure that support workers are visible to one another and to their managers. Records are a fundamental mechanism of *team-working*, which makes possible the development of coordinated strategies. Service agents are enjoined to strive toward an ideal of *substitutability*. That is, the performance of defined support roles, on the basis of recorded information and its interpretation in supervision sessions and team meetings, takes precedence over any relationship that the worker and the service user may form. While *friendliness* toward service users is generally advised and recognized as a useful individualizing force, *friendship* is strongly discouraged, and marks a transgression of professional boundaries.

### *Liberalism and the Antinomy of Law and Order*

Finally, all of these tactics of power may cohere in such a way as to play a part within a strategy that has very broad social and ideological ramifications. If the aim of these tactics is the production of competent citizens of the democratic state, the effects are more complicated, and less predictable. It is helpful in this context to recall Foucault’s insistence upon the “intransigence of freedom” (1982, 222). In particular, the prominent place of *rights* in the contemporary discourse of disability might allow for their employment against normalizing strategies. Foucault’s analysis implies that modern political rationality is always unstable: “[T]he main characteristic of our political rationality is the fact that this integration of individuals in a community or in a totality results from a constant correlation between an increasing individualization and the reinforcement of this ‘totality’” (1988, 162). The correlation can never be, as we might say, fully “sutured,”<sup>8</sup> for it

is founded on an antinomy between law and order. In Foucault's view, the conciliation of law and order "must remain a dream": "It's impossible to reconcile law and order because when you try to do so it is only in the form of an integration of law into the state's order" (1988, 162).

The antinomy of law and order may be correlated with an antinomy of rights and responsibilities. In the power relationships that I have been describing, compliance with the expectations of valued roles takes precedence over choice. Choice, a very high value, is at the same time a perpetual anxiety, a threat of disruption, unsettling of order, and a constant object of negotiation and correction. That is to say, the place of choice, in some circumstances at least, may mark the provocation of freedom.

### *Toward an Ethics of Difference*

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Consider the following strategies: lying in bed, refusing to go to work, shouting, kicking, smashing (or threatening to smash), being silent, choosing not to do anything, wearing unwashed clothes, not washing, not shaving, insisting upon the right to purchase certain items, and crying. Service agents will recognize some of these behaviors and be able to add many more examples of behaviors that "challenge services." It is possible that these behaviors are the performances of beings who seek to give expression to their autonomy. In the spirit in which Foucault removes Truth from its pedestal and reveals the very world-bound origins of knowledge-forms, we might show how freedom at first finds expression in "low" forms. With respect to these "challenging behaviors," is the question to be asked, "How might these acts of primitive rebellion be transformed, and sublimated into higher-order practices, which are worthy for citizens to enact?" I contend, to the contrary, that the question that ought to be posed is this: how can the range of possible actions that are available to people be extended, rather than constricted?

So-called challenging behaviors may be regarded as forms of resistance to the services that they challenge. People demonstrating challenging behaviors are resisting, among other things, a certain mode of individualization and a certain knowledge concerning who they are and what they should be. They oppose a dominating knowledge with their own unarticulated knowledge of the power/knowledge relationship to which they are being subjected. They act out of "subjugated knowledge"—disqualified, discontinuous, local, and popular knowledge that "owes its force only to the harshness with which it is opposed by everything surrounding it" (Fou-

cault 1980, 82). Corresponding to the conflict of power and freedom, there is a conflict of subjugating and subjugated knowledges.

Critical thinking unites disqualified, popular knowledge with nonsystematic, nonfunctionalist erudition, in order to elaborate a “historical knowledge of struggles” (Foucault 1980, 83). In his later work, Foucault describes such thinking as a form of ethical practice.

Foucault’s late essay on Kant suggests an ethics or *ethos* that is characterized by what Foucault calls a “limit-attitude,” an exploration of the “contemporary limits of the necessary,” whose aim is to go beyond them (1984, 43). This *ethos* employs “historical ontology” to question who we are now, analyzing the forces that have made us and continue to make us.<sup>9</sup> Historical ontology questions in a critical way; that is, in looking at the conditions that make us possible, it seeks to determine which are arbitrary constraints upon freedom, which can be changed in the furtherance of freedom (1984, 45). A critical ontology puts the question of power to power, acknowledges the power-embeddedness of relations between service agents and service users and *problematizes* them. “*How can the growth of capabilities be disconnected from the intensification of power relations?*” (1984, 47; emphasis added). An askesis (“exercise of oneself in the activity of thought” [Foucault 1987, 9]) of this kind questions all universals. In considering values and persons as “fictions,” that is, as products of knowledge-power, an exercise of this kind raises the possibility of fictioning different values, different selves.

The antinomy between law and order may be conceived at the level of community-based services as a fundamental and irreconcilable tension between equality and autonomy. Supported living valorizes equality, political and social inclusion, and normalization, all of which are categories that can be known and measured.<sup>10</sup> Autonomy escapes analysis and systematic knowledge. Autonomy is perhaps a subjugated knowledge of selves. There can be no system of social relations that escapes power relations. What we can do, with the help of Foucauldian tools, is to acknowledge and begin to describe tactics of power and strategies of freedom, and in doing so open up a critical space.

#### NOTES

1. *People with learning disabilities* is official U.K. parlance for people with developmental disabilities, intellectually disabled people, people with cognitive impairments. When people so designated have expressed a collective preference for a generic name, they have chosen *people with learning difficulties*.



2. I am writing from the standpoint of a support worker employed by a service agency. I am struggling, through writing, toward a critical understanding of my own activity and positioning. More generally, the term *we* in this chapter refers to something like an ideal type of social subject, to which each member of the social body is induced to conform. I am interested in how processes of normalization constitute different kinds of troubled “we.”

3. Colin Gordon describes governing as bio-politics, “as the conduct of living and the living” (1991, 8).

4. Tacit assumptions “impose unconscious boundaries between what is thinkable and what is not” (Barbara McClintock, quoted in Keller 1983, 178).

5. See John Law’s “Political Philosophy and Disabled Specificities” (1999). Law’s version of actor network theory offers a perspective on normalization that is indebted to Foucault, among others.

[M]any, perhaps most, disabled people are substantially disenfranchised in liberal democracies, and . . . to the extent that the current but partially fictional constitutional means for extending recognition to the disabled operate, they interfere to extend the franchise in very specific ways. This is because they make homogeneous assumptions about the character of the competent person. And those assumptions take it for granted that abled people are or should be: centred; that they are cognitively or (more specifically) textually/verbally oriented; that they are autonomous with respect to their surroundings; and that the opportunities available to them are broadly equivalent to those available to any other person. If a person measures up, or can be made to measure up, in these respects, then they become competent. If not, then they fail. All of which is, to put it mildly, a drastic divide. A divide, then, which resonates with the liberal concern with persons: but also operates as its dark side. (1999, 7)

6. In supported-housing environments, it is normal practice for staff to maintain a personal diary relating to each member of the household. This record is an important means of communication between supporting staff, concerning the activities of each service user, and the normative import of these activities.

7. It is a recurrent theme of Foucault that experience is not given, but constituted. See, for example, Foucault 1987.

8. For an account of the democratic possibilities resulting from incomplete suture, see Laclau and Mouffe 1985.

9. See note 2 above.

10. For example, PASSING (Program Analysis of Service Systems’ Implementation of Normalization Goals). See Wolfensberger and Thomas 1983.

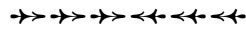
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CAROLYN ANNE ANDERSON



## Real and Ideal Spaces of Disability in American Stadiums and Arenas

In organizing “cells,” “places,” and “ranks,” the disciplines create complex spaces that are at once architectural, functional and hierarchical. It is spaces that provide fixed positions and permit circulation; they carve out individual segments and establish operational links; they mark places and indicate values; they guarantee the obedience of individuals, but also a better economy of time and gesture. They are mixed spaces: real because they govern the disposition of buildings, rooms, furniture, but also ideal, because they are projected over this arrangement of characterizations, assessments, hierarchies.

—FOUCAULT, *Discipline and Punish*

Foucault’s notions of government and discipline provide an alternative interpretive framework within which to examine the sociospatial construction of disability from a geographical perspective. Although geographers have begun to draw upon Foucault’s theories within their discipline (see, for instance, Driver 1985; Soja 1989; Philo 1992), few studies have focused specifically on the complex interconnection between Foucault’s work, geography, and disability (Butler 1999; Dear and Wolch 1987; Dorn 1999; Evans 1978; Gathorne-Hardy 1999; Philo 2000). By examining the history, design, and construction of sports arenas and stadiums in the United States, as well as the litigation that has recently been brought against some of them, I argue that geographies of these facilities mobilize the discipline and governance of disabled bodies. The real and ideal spaces that these built structures contain are architectural, functional, and hierarchical.

Beginning on May 8, 1997, the United States Court of Appeals for the District of Columbia heard legal arguments of the parties engaged in a dispute regarding access for disabled people to, and within, sports arenas and

stadiums that were constructed after the passing of the Americans with Disabilities Act (ADA). This hearing was the beginning of an ongoing legal battle between disabled people, the government, and builders of stadiums and arenas. The Paralyzed Veterans Association (PVA), a group of individuals with spinal-cord injuries, made this set of complaints in a class action suit against Ellerbe Becket, a large architectural firm that designs sports arenas. The case against Ellerbe Becket offers an example of how the way in which the built environment in the United States is planned, utilized, and navigated has been disrupted following the passage of the ADA. In this chapter, I examine the history of disability access in the United States in order to argue that geographies of the built environment reveal an intricate network of power/knowledge.

In order to begin this investigation, we need to have a picture of the built contexts (namely, stadiums and arenas) that are at issue. The spaces within sports arenas and stadiums can be problematic for anyone (disabled or non-disabled) to navigate. Flights of stairs and bleachers make movement difficult for some nondisabled persons and impossible for most people with mobility impairments. The installation within these buildings of nonescalator stairways and narrow seating arrangements, and the lack of nonfreight elevators in the buildings, exacerbates the problems that disabled people encounter when attempting to move within them. The sheer density of a packed arena can cause problems in navigating the grounds of the facility and viewing the activities.

In *PVA v. Ellerbe Becket*, individuals within the PVA alleged that they had been treated unfairly because in the defendant's stadiums or arenas they were only allowed access to wheelchair-designated areas. Seats located in these sections usually have obstacles that block sightlines to the activities on the stage or field. Members of the PVA claimed that areas that had been designated as "handicapped seating," in which wheelchair users were required to sit, had been designated as such because they were located in remote corners where the view of activities was obscured. In these areas (nicknamed "wheelchair ghettos"), furthermore, seats were located directly in front of wheelchair-using patrons, seats whose occupants might stand during an event. If this were to happen, the view of a wheelchair-using disabled person seated immediately behind the standing individual (or individuals) would likely be completely blocked.

Early litigation brought forth under the ADA made it illegal to deny access to a person on the basis of the individual's physical condition or ability. The interpretation and application of this law has historically worked to ensure that disabled people have equal access to employment, education,

public services, and public spaces. Beginning with the court case initiated by the PVA, however, disabled people have challenged the narrow scope of that interpretation of “equal access,” in favor of a broader one that encompasses access to aspects of culture, entertainment venues, and social events.

Litigation has ostensibly been presented to provide disabled people with equal access to events. This action is claimed to have a progressive rationale, namely, equality of access; however, this action also legitimates the view that disabled people are “not normal.” If we aim to change exclusionary environments through litigation, modification, and enforcement, we must deconstruct the meanings embedded in these exclusionary contexts, and the discourses that enable these meanings to persist. Equal access in the built environment involves a complicated set of issues, which require a greater intervention than does the construction of a ramp, the widening of a doorway, or the installation of an elevator.

By examining the issues that surround disability access, we can discern the ways in which physical ability is venerated in the United States. In doing so, furthermore, we uncover discourses that govern built environments and define how bodies will move within them. Existing classifications of what is normal and what is deviant are “built into” spatial planning. My aim in this chapter is to consider how the built environment, exemplified in the structure of the stadium and sports arena, becomes a monument to what is normal and what is deviant, where “disabled” subjects are the products of these discursive articulations.

### *The Discourses of Disability*



Whether you call it good business or demographic cleansing,  
the games are less accessible to the disabled, the elderly, and fans  
on budgets.

—TOM FARREY, “SCORE ONE FOR THE DISABLED”

The discourses surrounding disability in the United States have changed significantly over the past century, especially since the introduction of the ADA, which codified a new and institutionally recognized discourse. This legislative act has already left its imprint in the political and social landscape of the United States by virtue of the architectural “modifications” that the act stipulates must be made in the built environment in order to “reasonably accommodate” people whom it deems to be not “abled.” Insofar as the built environment is also a system of signs, these monuments give us a place to begin an excavation of this new, institutionalized discourse. Apparent

within these monuments are certain assumptions about how bodies should function, about the threats that anomalies in the system pose, and how these threats are correctable at the level of the individual body.

In 1990, the U.S. Congress passed the ADA, legislation intended to emancipate the millions of disabled Americans who lacked access to many public quarters due to physical and social barriers. The ADA was enacted into law in 1991, prior to the construction of many large arenas and stadiums in the United States. New stadiums in cities such as Boston, Buffalo, Philadelphia, Portland, Washington, D.C., and in Broward County, Florida, were built after 1991, and many were financed with public funds.

The PVA brought a class action suit against the owners of the Fleet Center Arena (Boston), CoreStates Arena (Philadelphia), the Marine Midland Arena (Buffalo), and the MCI Arena (Washington, D.C.) in May and June 1996, alleging that the seat designs of these facilities violated the ADA. By the fall of 1997, when the new stadium was opened in Washington, D.C., a federal district judge in Washington, D.C., found that the MCI Center violated the ADA because it failed to adequately create “proper access to the disabled in its seating plan.”<sup>1</sup> This class action lawsuit brings into question what is meant by “lines of sight comparable to those for members of the general public” (*Ellerbe Becket*, sec. B-5). The plaintiffs in the case argued that wheelchair-using patrons have the right to an “enhanced” line of sight—that is, a view of the performance floor that remains unobstructed when patrons, who are seated in the rows in front of them, stand. The architects of the MCI Center claimed that enhanced sight-lines are not a requirement, arguing that no authoritative determination existed, in statute, in the attorney general’s regulations, or in the advisory proposal. The judge residing over the case ruled in favor of the defendants, arguing that enhanced sight-lines were not required; in addition, the judge explicitly criticized the Federal government for not providing any solid guidelines regarding the interpretation of the statutes. The judge found that the defendant, who was unaware of any ADA requirement stipulating that a wheelchair-seating location must provide enhanced lines of sight, acted in “good faith” in its design and construction of the arena (Dvorchak 1999).

In the case of the Rose Garden (Oregon), the architectural firm was not forced to renovate the current stadium; the firm agreed, however, to design future stadiums and new arenas in ways that allow spectators who are seated in wheelchairs to have full view of actions occurring on the performance floor, even when other fans stand (Conrad 1997). The settlement clarified the standard, and ended confusion regarding enhanced sight-lines. As part of this settlement, Ellerbe Becket agreed to provide annual reports on the

status of compliance for the years 1999, 2000, and 2001. To ensure compliance, the reports had to describe the project name and location, the number and location of wheelchair seats at the venues, and the provisions made for lines of sight over standing spectators. Although this settlement directly applies to the Ellerbe firm, it sets a legal precedent for other designers; indeed, subsequent to this settlement, the president of Ellerbe remarked that “every other architect and engineer would look to the settlement as a way of keeping themselves out of court” (Conrad 1998). The reaction to the settlement of the counsel for the PVA was cautious. As the PVA’s counsel put it, the settlement indicated a “sea change in focus and attitude” on the part of the Ellerbe architectural firm; it remained an “open question,” however, whether this change would “permeate to other firms” (Conrad 1998).

In addition to the enhanced sight-line issue, the court ruled in favor of improved seating distribution. Wheelchair access in the lower sections of the MCI arena was not adequate due to the dispersal of the seats. Unlike the upper level, whose wheelchair seating was distributed equally throughout the bowl, the lower level had few wheelchair-accessible seats in its center section. The court remarked that “the spaces in the lower level are ghettoized in the end zones areas” (Carelli 1998, 1). The court concluded that less than 40 percent of the wheelchair spaces in the MCI arena, most of which were located in end zone areas, had unobstructed lines of sight. Thus, the court required the defendants to submit a proposed change in design within thirty days of the ruling (Carelli 1998).

The rulings in these landmark cases have brought about promised changes in the subsequent construction of stadiums and arenas; however, these rulings have not affected the design and construction of stadiums and arenas that were erected prior to their promulgation. In addition, these rulings focus on the financial issues at stake in the modification of ticket-selling practices.

The ADA allows arenas to fill wheelchair-seating areas (which usually consists of an open concrete slab) with folding chairs if wheelchair users do not use all of the spaces in them. Due to the width of a wheelchair, at least two rows of regular seats would need to be removed, in order to give the disabled person room enough to maneuver. The removal of seats is done at a significant cost of lost ticket revenue to the arena. To illustrate, by using a ratio of five to one, a wheelchair user and a companion sitting in two one-dollar-seats could occupy the equivalent space of ten nonwheelchair seats, potentially costing the arena eight hundred dollars. A person using a wheelchair placed in a five-dollar seat in the upper deck would cost the arena only



forty dollars. In the case against the Rose Garden, wheelchair users provided the court with anecdotal evidence that showed that ticket sellers had steered them away from the one-hundred-dollar seats, in favor of seats located in less expensive sections of the facility. In addition, some wheelchair users testified that they had been told by arena ticket vendors that there were no seats available (Green 1998, 6).

Despite claims by the owner of the Rose Garden that arena officials always set aside enough wheelchair seats in a variety of locations to meet demand, the judge wanted to take a closer look at ticket sales. Ashbel S. Green writes in the *Oregonian* newspaper,

Many seats closest to the court are not available to wheelchair users because the Blazers sold them to season ticket holders. Few, if any, season ticket holders are disabled. . . . The result is that on a game to game basis, 133 of the 191 wheelchair seats are not available to wheelchair users. (1997, 7)

According to Green, resettling more than one thousand season ticket holders in less desirable sections could potentially cost the arena more than \$2 million a year (1997, 7). In addition to season ticket holders, another key moneymaker for arenas are executive suites, which corporations lease to entertain their clients. The Rose Garden adopted a policy that disabled people were required to notify the arena forty-eight hours in advance if they planned to attend an event and utilize a luxury executive suite. In his ruling, the judge stated that “there is no reason why persons with disabilities should have to call in advance to warn people they are coming as if they were bearers of a contagious disease” (Green 1997, 7). Other remedies proposed by the court provide additional examples of how a network of power corrects itself, especially with respect to the exchange of capital. The stadiums stand to lose money for each seat they sell to wheelchair users. It seems somewhat foolish, therefore, to have arenas self-monitor their own progress toward making seats accessible.

The impositions made by the courts may someday influence the built environment, guiding architectural firms in planning and designing future stadiums; in addition, it is hoped that these rulings will affect the space within current stadium structures. If the creation of equal access to stadiums and arenas were to result in decreased profits for the owners of them, this would provide a good motive for the owners to resist transformation of the public perception of disability, as well as changes in the building requirements of those structures themselves. It becomes important, therefore, to

examine how disability is culturally and spatially constructed through a host of factors, including the ways in which we talk about it, the treatment that we give it, and how we write about it. For discourses systemically form the objects to which they refer. In short, disability is not simply a matter of medical impairment, a physical condition owned by a body; rather, disability is social and spatial impairment that environments (discursive, architectural, economic, and so on) produce.

### *Able-Bodied Keepers*

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The space reserved by society for insanity would now be haunted by those who were “from the other side” and who represented both the prestige of the authority that confines and the rigor of the reason that judges. The keeper intervenes, without weapons, without instruments of constraint, with observation and language only, he advances upon madness, deprived of all that could protect him or make him seem threatening, risking an immediate confrontation without recourse. In fact, though, it is not as a concrete person that he confronts madness, but as a reasonable being, invested by that very fact, and before any combat takes place, with the authority that is his for not being mad.

—FOUCAULT, *Madness and Civilization*

Disability has been consistently defined within a medical conceptual framework (see Linton 1998; see also Davis 1995; Thomson 1997). Within this medical definition, a “disability” results when people with physical, sensory, or cognitive impairments confront social or spatial constrictions. Recent efforts to enlarge access in the United States have codified this medical discourse insofar as the federal government has created a definition of who is disabled and who is not, and what “rights” can be assigned to people in each of those groups. In order to be considered disabled under the Americans with Disabilities Act (ADA), an individual must have a condition that significantly impairs one or more of the individual’s functions of daily living. In order to “prove” disability status and attain services or legal protection under the ADA, individuals may be required to produce medical documentation that states the nature of their respective impairments. Disability, as a legal qualifier, is articulated in terms of a medical diagnosis. Many disabled people (and their allies) have advanced arguments—legal, academic, and personal—that challenge this medical perspective. The emergence of these arguments enables us to see how disabled people have traditionally been disciplined and the larger system in which these catego-

rizations are produced. In fact, it is possible to trace a genealogy of the ideas and practices that, from the early part of the twentieth century, constituted and marginalized the group “people with disabilities” in the United States.

In *Madness and Civilization* (1965), Foucault traces the course of madness through the centuries. We can expand upon this tradition of tracing the placement of marginalized groups through history, beginning with the early-twentieth-century confinement of certain people in asylums.

Foucault argues that the seventeenth-century confinement of madmen was motivated by a desire to discipline these people and keep them separate from “normal” society. Later, to various degrees, the insane were physically liberated from the asylums. They were, nevertheless, placed under a new kind of control: a moral education and psychiatric discourse. Foucault argues that the inculcation of this education and the exercise of this discourse actually rendered the insane more confined than had physical incarceration because their minds (rather than their bodies) became subject to treatment (1965, 198). The insidious medical discourse of psychotherapy, in particular, became another means through which power subjected the insane. By talking in therapy sessions, the insane person was compelled to confess his madness to his psychiatrist. Though no longer confined within the walls of the asylum, the insane person nevertheless remained the subject and object of power, construed as knowledge of madness and sanity, which was confirmed by his overseeing doctor.

The beginning of the twentieth century saw a drastic reorganization of labor in Western societies. Work became increasingly more urbanized and industrialized, which directly impacted upon disabled people. As Mike Oliver explains it, “The operation of the labor market in the nineteenth century effectively depressed handicapped people of all kinds to the bottom of the market” (1990, 28). This reorganization of labor resulted in the establishment of special institutions and practices (such as asylums, workhouses, and other programs), operated by religious groups and other charitable organizations, which separated disabled people from mainstream society (29).

Brad Byron notes that institutions of the late nineteenth and early twentieth centuries elaborated the discourse of disability in the United States.

Beginning around 1890, with the creation of the first institutions most aptly referred to as “hospital schools” and the opening of the first programs for the vocational training of “cripples,” an approach to the problem of disability emerged that became known as rehabilitation. (Byron 2001, 133)

Disabled people were confined to a “space of *unable*” that was analogous to the “space of *unreason*” (the negative valence of the “space of *reason*”) that the insane had previously occupied. This space of *unable* signified the opposite of health, family, gainful employment, and productive communities that allegedly existed among the “able-bodied.” In the emerging capitalist order, nonproductive and dependent populations were confined in the hope that they would be “rehabilitated.”

Following World War I, the rehabilitation movement was advanced by the influx of returning disabled veterans. “The reformers who led this movement identified what they called ‘crippledom’ as a serious social and economic problem” (Byron 2001, 133). “Cripples” were not only individuals with physical illness and mobility problems; the term *cripple* also indicated economic dependence and reliance on charity. Elimination of this dependence became the focus of the rehabilitation movement. In 1918, the U.S. government passed the Soldier’s Rehabilitation Act, which provided vocational training to returning veterans. The adoption of this legislation caused a stir of debate about the rehabilitation of people who had been injured in civilian workplaces, as well as the rehabilitation of veterans. This debate, in turn, led to the Vocational Rehabilitation Act of 1920, which gave civilians the same access to rehabilitation services as veterans (Hickel 2001, 246).

In the United States, during World War II, women, minorities, and disabled people were given many of the factory jobs that “able-bodied” men who had gone to fight the war had vacated. Given the booming postwar American economy, replacement workers (many of whom did not want to relinquish their jobs after the war) were kept on at most factories; in addition, some returning veterans resumed jobs that they had held before going off to fight. Many of these veterans returned with newly acquired impairments, however, increasing the population of working-age disabled people, as well as the need for more comprehensive rehabilitation services.

The 1960s and 1970s brought about massive social upheaval in the realm of disability. More laws were put into effect in order to ensure the rights of disabled people in the United States. These include the Rehabilitation Act Amendment of 1973 and 1978, the National Housing Act Amendment of 1975, the Education for All Handicapped Children Act of 1974, and the Social Security Disability Amendments of 1980. The introduction of this legislation, and the legal changes that ensued, created an infrastructure conducive to additional disability litigation.

In the 1970s, a group of disabled students at the University of California

at Berkeley came together to create a group called the “Rolling Quads.” These students moved out of the Student Health Center, which had served as their dormitory, and began to integrate themselves into the community. This small group of disabled individuals has achieved an almost legendary status within the American disability community and has often been credited with the inception of the independent living movement in the United States, as well as the American disability civil rights movement. Prior to the advent of these movements, disabled people in the United States who were without wealth or family had been forced to live in institutions. These movements began an era of “liberation” for many disabled people, especially disabled people who had never been given the opportunity to live outside of institutions. The Rehabilitation Act Amendment of 1978, which led to the creation of independent living centers throughout the country, furthered this “liberation.”

The Rehabilitation Act Amendment and other governmental acts not only “liberated” disabled people, they also initiated changes to the landscape of the American city: wheelchair ramps were built, accessible parking spaces were added to parking lots, and wheelchair-accessible toilets were increasingly installed in public restrooms. These architectural and infrastructural changes provided disabled people more freedom to move within the built environment. Furthermore, these changes to the built environment dovetailed with an increase in the popularity of the independent living movement and the disability civil rights movement due to an influx of recently disabled American citizens. For during and after the Korean and Vietnam conflicts, thousands of men returned to the United States with impairments that they acquired in these wars.

Within a century’s time, the social situation of disabled people in the United States shifted from complete confinement in institutions to alternative living options that were created by the formation of independent living centers. This history shows the transition from an era of confinement toward the era of disability “freedom,” and provides a historical perspective with which to approach the issue of seating for disabled people within stadiums and arenas. For in the early twentieth century, an individual or group would not have had the option to bring forward a lawsuit against an architectural firm that does not incorporate “enhanced sight-lines” for wheelchair users into the design of its arenas. In short, there has been a dramatic change in the “rights” and options available to disabled people.

It is interesting to note that the U.S. Department of Justice Civil Rights Division has jurisdiction over the matter of enhanced sight-lines. The Justice Department is that branch of the government which issues statements

on enhanced sight-lines for wheelchair users (Department of Justice 1998a, 1998b) who attend events in stadiums. This fact alone denotes a change, on the part of the U.S. government, in both attitude and practice toward disability. Many view this change as progressive. It is, however, important to view the “disability civil rights” discourse *as a discourse*, itself codified in a network of power. Indeed, I contend that civil rights movements are not as “emancipatory” as they are claimed to be. I shall, therefore, now consider how this supposed increase in “rights” operates to discipline bodies.

### *The Disabled Body as a Docile Body*



Ruley, who has taken the freight elevator to and from [the arena, says] “You literally roll in with the garbage and roll out with the garbage.”

—TOM FARREY, “SCORE ONE FOR THE DISABLED”

Foucault departs from conventional ways of studying history, arguing that studies of the past are consistently quixotic in nature. For instance, science is claimed to discover “truth” and laws that accurately represent the world; yet even a scientific “truth” remains valid only until a truth with greater explanatory power replaces it. Often, a collection of “laws” and “truths” allows us to believe that we are “progressing,” from similitude to similitude, when in fact we are merely becoming more entangled in the labyrinth of our own representation. Foucault believes that by uncovering the relationships between words and things, we can locate the sites at which ideas of normalcy and deviance are taken for granted and where representations of truth change. Discontinuities cause disruption, and these are the moments when discursive production (for example, the production of ideas around health and illness, normalcy and deviance, able and disabled) becomes visible. Foucault’s archeological strategy excavates ways in which these ideas are cemented. The periods in which these changes take place break the cycle of continuous belief.

Like the social position that “the insane” came to occupy upon their release from the asylum, the position that “liberated” disabled individuals occupy today is a marginalized one. The current discourse that governs disabled people is not one of morality or psychiatry; rather, it is a discourse of ability and health. Disabled people are free to move about the city; yet, in some ways, they are less “free” than they were in the past because their minds are subject to a medicalized pathology that many of them internalize. Monuments in the built environment define this pathology. The construc-

tion details of arenas and stadiums, for instance, define the bodies of sports fans in conformity with certain specifications of height, weight, mass, and ability. People whose bodies do not fit these cultural standards are positioned *outside of* the realm of the normal, legitimate, virtuous. In fact, the stadium becomes a site for the production of power and knowledge as “discipline proceeds from the distribution of space” (Foucault 1977, 141).

In *Discipline and Punish* (1977), Foucault examines not only how bodies are treated, moved, and disciplined in institutions like the prison, hospital, or school; in addition, he examines the strategies of power that bodies themselves adopt in relation to institutions. For inmates of the prison, the microphysics of power in the prison do more than produce an obligation of prohibition: the prisoner has an obligation to behave in a certain way if he desires an early release. Therefore, the terms of power grip the prisoner on a deeper level than had earlier forms of punishment. Now the prisoners’ bodies are invested with a power that is transmitted by them and through them.

One can apply these insights to the situation of disabled fans who attend sporting events. For power works through these individuals. The disabled body becomes a docile body, subject to improvement and usefulness, an object and target of power. To illustrate how disabled people become implicated in their own “social Otherness,” let us analyze one of the unenforceable rules generated by recent stadium litigation. To meet sight-line requirements, many stadiums across the country have adopted a “no-stand” policy with respect to seats that are located in front of the wheelchair section of the spectator seating. An explanation of this “no-stand” policy is that people are not “allowed” to stand in front of wheelchair users. This “policy” is either explained to the participant upon the purchase of a ticket in the no-stand section, or told to the attendees seated in this area by the enforcing officials or event attendants. For obvious reasons, this policy is difficult to enforce. To avoid problems that might result due to the enforcement of the no-stand policy, some arenas have adopted a “no-sell” policy for the seats in front of wheelchair sections. In other words, seats in front of wheelchairs remain unsold. However, even if tickets are not sold for seats in front of the wheelchair section, no one prevents people from actually sitting in them. Indeed, these seats often come to be occupied by sporting fans who inevitably stand and block the view of wheelchair users who are seated behind them.

Most of the people at events such as basketball games are spectators: they watch the plays with their eyes, they cheer the team with their shouts, they jump to their feet, and wave their arms in the air. That is the manner

in which the majority of the general public observes a sports event. If, however, you are a quadriplegic person, your experience is significantly different.

First, to access the event, you must find the accessible entrance to the facility, because at some facilities not all entrances are wheelchair accessible. Then you must navigate your way to your seat. You are seated in an individualized section used only by other wheelchair users. Since wheelchair seating allows for only one companion per wheelchair user, additional nondisabled friends or family members who come to the event with you must sit in another section of the facility. Maybe shouting and cheering are not options for you because you use a ventilator to breathe; furthermore, jumping up and down and waving your arms is a physical impossibility. You have full working capacity of your vision; however, your line of sight is completely blocked by the row of people standing up in front of you.

This experience is beyond the comprehension of most sports fans. Even those of us who take the effort to conceptually inhabit the experience of such a disabled spectator cannot have a similar experience unless we are similarly disabled. In short, it becomes evident that “reality” for most people is still heavily inscribed in a social discourse of normality in which people’s bodies should in general conform to certain norms with respect to size, shape, and ability and should in particular be ambulatory. People whose bodies fall outside of these norms become anomalies.

In a world of no-sell and no-stand ticket policies, the disabled person must enforce her own line of sight. While she is free to move outside of the hospital or institution in the post-ADA era of disability emancipation, she does not have freedom to attend a cultural event in a way that would equal the freedom that the nondisabled public enjoys. A wheelchair user who attends an event in a stadium is placed in a specified area, which is spatially not unlike the patient who confesses her insanity on the psychiatrist’s sofa. Her spatial position subjects her to those with knowledge/power of able-bodiedness and privilege. She becomes responsible for speaking and confessing her disability. Because the wheelchair user at the stadium event must (repeatedly?) remind the people who are seated around her that she cannot stand in order to see, the discourse of normality that currently governs the design and construction of stadiums ensures that she remains compelled to inform them about the specifics of her physical difference. In other words, like a patient in confession, the person in a wheelchair becomes both the subject and object of power. Insofar as the disabled person is compelled to enforce her own relation to this normalizing discourse, power works through her body. Moreover, insofar as she has no choice other than to yell



at the people in front of her (“Hey, I can’t see. Would you please sit down?”), and in doing so defines herself as different from others, she is further marginalized.

### Concluding Remark

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This examination of the politics of stadium seating reveals the link between Foucault’s project and the sociospatial construction of disability. If spaces in the built environment can be viewed as monuments in which ideals of normalcy and deviance are cemented, an archeology of sports arenas in the United States reveals many discontinuities, including the changing role of the disabled person and how, within this articulation, the disabled body becomes “imprinted by history” (Foucault 1984, 83).

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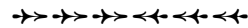
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## Foucault on the Phone

### *Disability and the Mobility of Government*

*“Hello, Foucault? Where Are You?”*



Telecommunications is the locus of digital interactive communications that are fast becoming central to society at the commencement of the new millennium. Advanced telecommunications and computer networks are the nervous system of a wide variety of contemporary communications and media forms, including the Internet, new modes of voice and text telephones, and digital broadcasting. Digitization and convergence have merged technological systems such as the computer, telephone, television, radio, book, and newspaper. Increasingly, information and entertainment, goods and services, education and health, and travel and recreation are expected to reach us through a stream of zeros and ones, through our phone lines and radio waves. In this chapter, we suggest how Foucault’s work can be used to scrutinize the interrelatedness of emerging forms of telecommunications, disability,<sup>1</sup> and government. In particular, we aim to show that Foucault’s insights on contemporary governmentality provide an especially valuable lens through which to examine how new developments in telecommunications produce disability and to consider how the configuration of that developing technology might be reframed and contested.

Following Foucault, one can view telecommunications as the vascular system of a network of governmentality that is comprised of the state, parastatal organizations, corporations, nongovernmental organizations, and local sites of civic citizenship. Telecommunications is decisive in, and integral to, power and rule in “postmodern” society; as many analysts (see, for example, Castells 1996–98) have observed, furthermore, telecommunications has been a constitutive part of globalization at the end of the twentieth

and beginning of the twenty-first centuries, something presaged by theorists of postindustrial societies such as Bell (see, for instance, Bell 1973). Given the present velocity of circulation of capital and investment, finance and the economy would not endure without digital communication networks. The participation of people with disability in this complex expansion and thickening of globalization has, however, been governed by narrow norms and remains the jurisdiction of certain countries and their governments. Benefits of globalization, such as they are, have been unequally shared by people with disabilities. As financial and political systems have globalized, furthermore, disability has been built into technological networks.

The markets and institutions of communications have been substantially reshaped under the sign of deregulation and liberalization (Braithwaite and Drahos 2000). Telecommunications has been a strategic site in this regard. Telecommunications law, regulation, and policy have increased in complexity; and in many countries, quasi-governmental bodies have been formed to enforce and embody this disciplinary ensemble. (We could point, for instance, to the various legislative and policy developments in richer Western countries, which have been taken in the name of freeing up the economic market: a series of court decisions in the United States that culminated in the 1996 Communications Act; the 1997 Australian Telecommunications Act; the 1993 Canadian Telecommunications Act; British reforms since the mid-1980s; successive European directives; and the 1997 World Trade Organization agreement on basic telecommunications.) Coeval with these developments is a new notion of regulation, one variously termed “self”-regulation, “co”-regulation, or “light”-touch regulation. The motivation for this new notion of regulation is the desire for corporations to regulate themselves. That is, since businesses deliver goods and services to customers, they are claimed to be in a better position to set out the minimal rules of conduct that would least interfere with market prerogatives, as conceived within neoclassical economics, than are bureaucracies associated with the state (for critiques of neoclassical economic approaches, see Hills 1986; Babe 1995; Aufderheide 1999; Barr 2000; Wilson 2000). When the market becomes self-governing in this way, it has removed the government of many spheres of life from the state. Foucault explains this kind of shift of government in this way:

It is possible to suppose that if the state is what it is today, this is so precisely thanks to this governmentality, which is at once internal and external to the state—since it is the tactics of government that make possible

the continual definition and redefinition of what is within the competence of the state and what is not, the public versus the private, and so on. (2001, 221)

The reshaping of telecommunications and its convergence with other digital technologies has been accompanied not only by juridical and self-regulatory market discourse; in addition, dominant social discourses have accompanied the reconfiguration of the technology. One feature of these social discourses is the constitution of the technology as liberatory for its projected users; paradoxically, the technology is also held to be “value free.” In the terms of these social discourses, however, people with disabilities are often valorized as a special case in point: technological solutions are held out for their potential to abolish or ameliorate the disability that is seen to lie within the individual. That the social and discursive shaping of technologies proceeds via a promissory note that they will confer unalloyed benefits upon people with disabilities reveals a fundamentally flawed approach to disability. This approach rests upon the model of disability that construes it as the static, biologically originating deficit of a given individual, as opposed to a contingent phenomenon that is constituted through social structures and discourses (see Fulcher 1989; Corker 1998; Corker and French 1999).

It could be argued that governmentality operates through digital communications systems in order to encourage the proliferation of mediated communications, producing the citizen as consumer, whose information may be monitored, captured, and analyzed, who will be “always on,” and thus available for marketing opportunities that are delivered in subtle ways. Within this system of digital governmentality, disability is created as the objectified other, constituted as a “deficit,” and deviant. Via governmentality, bodies are regulated, most especially deviant bodies. Regarded as deviant bodies, people with disability are seen to lack full attributes of personhood, attributes that are necessary if one is to count as a fully fledged citizen. Consider, for instance, that often the consumer-citizen of telecommunications is a person who buys things *on behalf of* a person with disabilities, rather than the person with disability doing so herself.

Despite the exclusionary construction of the consumer-citizen, there is no doubt that many people with disabilities are users of telecommunications, and are in particular interested in digital mobile telephony and much-vaunted third-generation mobiles. However, scant attention has been paid to the diverse needs of people with disabilities in the design of digital mobile telecommunications. In response, the disability movement, and all too few

commentators, have pointed out the implications of such disabling technologies for equality—warning of the problems in marginalizing disability in an information age.

### *Who Put Disability into Mobiles?*



In the late nineteenth and twentieth centuries, people with disabilities were seldom considered in the development of telecommunications. Alexander Graham Bell had in fact invented the telephone to assist deaf people, yet this dimension of history is rarely, if ever, reflected upon (nor is Bell's own role in moralism; see Bayton 1996). From its introduction as a communications device that was primarily used by business, or by rich domestic subscribers, the phone became part of a nation-building project in most countries, complementing cultural technologies such as postal services, the press (Anderson 1983), telegraphy, radio, and eventually television. The nation-building project was symbolized in the dominance in most Western countries of postal-telegraphy-telephone (PTT) organizations, which were in general owned and operated by the state along public service models (as in Europe), although in some countries (the United States and Canada, for example), private monopolies played a role (Brock 1994; Wilson 2000). Availability of telephone service to all of the citizens within the boundaries of the nation-state (an especially important goal of mid- to late-twentieth-century telecommunications policy) was referred to in many countries as "universal service." We wish to note here, however, that people with disabilities were systematically excluded from this nation-building project, as well as the notion of citizenship that the project entailed.

Throughout the twentieth century, telecommunications grew in importance as part of a system of governmentality. Historically, availability of voice telephony was the central preoccupation of commerce and the state until the 1960s, when access to data communications for business (followed by household and individual access) achieved importance—especially with the diffusion of facsimile and computer network technology. In short, access to telecommunications allowed the state to include and infiltrate into the "private" sphere, into the texture of people's everyday lives (Samara-jiva 1997). To give one example, home banking became possible because people could use intelligent telecommunications networks to conduct transactions from any phone, including ones at their homes. When, in the past, people had been away from the phones in their homes and workplaces, or even the stationary pay telephones in public places, they had not been con-

tactable and, one might therefore suggest, had inhabited the interstices of government.

One of the most significant transformations in telecommunications and government in the last two decades of the twentieth century is the addressing of mobility. The emergence of mobile telecommunications can be traced back to radio telephones, which were first used by military, ship captains, police, or emergency services. In the 1970s and 1980s, the citizens' band (CB) radio became popular (evidenced in the film *Smokey and the Bandit*). CB radios, at one time used almost exclusively by long-haul truck drivers, came to be adopted by ordinary car drivers. Mobile phones, a more easily carried and portable device, began to be commercially introduced in a number of countries in the 1980s, and were cheerfully referred to by their users as a "brick" (even at that time the mobile phone was difficult for many people with disabilities to hold and use). This system was based on analogue technology (AMPS), which is now called "first generation" mobile technology. During the 1990s, digital mobile phone systems were introduced around the world, promising better voice quality, data transfer rates, more efficient use of scarce radio spectrum, and security from interception of calls. The two dominant systems implemented were the Global System for Mobiles (GSM) system (in Europe, parts of Asia, and Australia), and the Code Division Multiple Access (CDMA) system (in the United States, and other countries).

By the twentieth century, these digital mobile phones had enjoyed extraordinary success, with ownership rates outstripping fixed phone ownership in many countries. Success of this consumer product may be attributed to a number of factors: mobility, which allowed people to be contacted regardless of their locations, rather than force callers to wait until those people would be in close proximity to fixed phones; individualization, which allowed a given phone to be associated with a certain individual, rather than a house, office, or other dwelling; fashionability, because mobile phones have very much become part of the semiotic system that shapes subjectivity—for example, the ring-tone of a phone can be programmed (and thus taste in music can be publicly signaled) and the color and look of the phone can be chosen and modified (permitting aesthetic sense, cultural values, and wealth to be displayed); and, lastly, mobility of data, which allows voice and text communications to be combined.

From the perspective of governmentality, the rapid refashioning of telecommunications as *mobile* allows power to operate along different planes, surfaces, and (in the words of Gilles Deleuze and Félix Guattari 1987) "lines of flight." At present, people are potentially, and easily, identifiable as



tangible individuals for surveillance or marketing (or both), at any time of the day, wherever they are in the nation-state or, for those who can afford global roaming, satellite phones, and travel, wherever they are in the world. An important parallel to the development of mobile telephony is the introduction of the global positioning system (GPS) technology, which allows the location of a given individual to be pinpointed. A new feature of some recently manufactured automobiles provides the example of the combination of global positioning technology with mobile telephony. These cars are equipped with safety airbag-inflation mechanisms that, upon inflation, trigger courtesy calls from their manufacturers' service centers to drivers in order to find out what sort of assistance they require. In the absence of a reply from a particular car's driver, emergency vehicles are given the location of the car and dispatched to the scene.

Like other forms of telecommunications, mobile telecommunications has conferred both ability and disability. For instance, mobile telecommunications has opened up new spaces and uses of communications, which are formative of the lives and subjectivities of people with disabilities. Short Messaging Services (SMS) were an unexpected, but significant, development in second-generation mobile phones, not least for people with disabilities. Deaf people, for instance, have been able to avail themselves of SMS services as a relatively cheap, easy-to-use, any-to-any communications technology for communicating with other Deaf and hearing people. Text phones, known as teletypewriters (TTYs) or telecommunications devices for the Deaf (TDDs), are the technology that has been used since the 1980s by Deaf people for communicating over the telecommunications network, though government and companies were very slow (especially prior to the mass take-up of the Internet) to recognize the validity of this method of text communication.<sup>2</sup> Given that many (hearing) people who do not own text phones are the owners of mobile phones, Deaf people can communicate short messages with these individuals in addition to text phone (or Internet) users. Two drawbacks of this development in communications technology are first, mobile telephones have cramped keyboards that render them difficult to use; and second, their operation requires a greater number of keystrokes than does the operation of a text phone. Indeed, the introduction and development of "second-generation" mobiles has given rise to a significant number of sites of contestation on the part of people with disabilities that intersect with other sites of social conflict.

The best known of these contested sites involves the relation between hearing-aid users and GSM mobile phones. In the early 1990s, subsequent to the development and commercial introduction in a number of

countries of the new digital mobile system, GSM digital technology emitted a high level of electromagnetic interference. This interference had the potential to cause a buzzing sound in hearing aids, as well as to make the phones difficult for people with hearing aids to use. Phone companies internationally, the state, and regulators, put a great deal of effort into “managing” the public outcry. They appear to have been motivated to do so by a concern that this new, expensive technology might not be adopted by consumers, despite widespread support from policymakers. In order to avoid this outcome, and given the wide range of technologies that emit such signals, company and state officials directed their attention toward the creation of a need for hearing-aid users to cope with higher levels of electromagnetic emission. Hence, a European standard was introduced in 1990 that made hearing aids immune from regulations governing the emissions from mobile phones. In turn, this European standard formed the model for a similar Australian standard. In addition, research was conducted on ways to remove the source of emission farther away from the hearing aid; as a solution, “hands-free kits” were eventually designed for hearing-aid users. Hands-free kits were not sufficient to provide access to digital mobile phones for all users, so the disability movement adopted other tactics. In Australia, for instance, resort was needed to human rights and antidiscrimination law in order for the matter to be successfully addressed: the Human Rights and Equal Opportunity Commission (HREOC) conducted a public inquiry into the matter, which resulted in a conciliation some eighteen months later (HREOC 2000). Unfortunately, the problem of emissions remains and is not easily solved by the alternative second-generation digital mobile telephony technology—CDMA (Code Division Multiple Access)—which in any event is not widely available in jurisdictions outside of the United States. What effectively occurred in this case was that phone companies were forced to contemplate a costly redesign of the technology as a whole (on which they demurred), or design modifications of the technology.

If disability and accessibility had been an everyday part of how phone companies, government departments, standards-setting bodies, and regulators envisioned forms of advanced telecommunications, this sort of technology debacle would have been avoided. If the needs and aspirations of people with disabilities were better understood, and if people who are hard-of-hearing and use hearing aids had been integrally involved in the design, policy, and implementation process in this particular instance, the technology would have been more accessible from the outset, and the corporations that produce it would have faced a better outlook in terms of their finances.

Furthermore, states and their regulators would not have been reluctantly compelled to take some form of action on behalf of aggrieved citizens who felt that they had been excluded from a new digital mobile telecommunications network.

The wireless access protocol (WAP), one of a number of developments under the rubric of 2.5G (where *G* means “generation”) mobile phones, was introduced at the end of the 1990s. WAP was the forerunner of “always on” mobile telecommunications, providing text and Internet communications and e-commerce for users, though take-up of services was initially slow. The so-called third generation (3G) mobile technology, which has been hyped even more than WAP, promises to bring broadband capabilities (such as interactive video) to consumers, and has already required billions of dollars of investment in spectrum before infrastructure is actually constructed.

After Foucault, 3G mobile can be regarded as a juggernaut of the values that we find inscribed in technology, as well as a totem of governmentality. In this technology, the dreams of video communication, which have been the stuff of utopian science-fiction and futurology for decades, will be realized. To be sure, 3G mobile does have the potential to improve the lives of people with disabilities; however, it could in addition be exclusionary. Tony Shipley and John Gill note that 3G mobile might facilitate “remote [destination] location and guidance (giving enquirers personal information on how to reach their destinations, with the service center pin-pointing their locations automatically)” and “remote interpretation for deaf people, by Sign Language or Lip-speaking (as soon as visual displays of adequate size and definition are available)” (Shipley and Gill 2000, 8). Nevertheless, Shipley and Gill also identify problems with 3G mobile technology. To briefly mention some of these: first, the wireless transmission technology used with 3G may also cause problems of interference and noncompatibility with hearing aids; second, the continuing trend toward smaller mobile phones is not helpful for many people with disabilities; third, services like automatic answering, voice mail, and call progress announcements (facilities based in the network) are not helpful for blind people or people with vision disabilities; fourth, many Internet-based applications, designed to be used with 3G mobiles, are visually oriented and thus exclude blind consumers (Shipley and Gill 2000, 8–10). In response to these emerging concerns, Shipley and Gill call for the establishment of a “culture of inclusion” in the design and standards-setting process (and telecommunications industry more generally); in addition, Shipley and Gill call for the establishment of a forum for discussion of inclusion and accessibility issues with industry,

the aim of which would be to ensure that “disabled and elderly people are enabled to participate in the benefits of third generation mobile communication systems from the outset, as discriminating consumers but not discriminated against” (Shipley and Gill 2000, 28). We believe that this proposal has merit; we would, however, also critique the implicit expectations of the notion of inclusion, by questioning a ready acceptance of social order, which creates inclusion as a necessity.

### *Government, Disability, and Mobiles*



To situate the social and discursive construction of mobile disability and its power relations, we turn in this section to a fuller consideration of Foucault’s notion of governmentality. As we showed in the previous section, mobile telecommunications have often been simultaneously considered a value-neutral device, on the one hand, and a technology of freedom for people with disabilities, on the other. Mobile telephony has, however, also been critiqued for excluding people with disabilities. What we wish to explore is the way in which mobility of communications is implicated in the *governing* and *disciplining* of disabled bodies. In particular, we argue that contemporary telecommunications, with its centrality for networked new media, may be read as a technology of normalization.

Foucault argues that the development of bio-power—or the power over life—has the effect of the “growing importance assumed by the action of the norm, at the expense of the juridical system of the law” (1979, 144). Far from representing the view that law ceases to be important, Foucault’s argument is that law is increasingly invested with norms and operates more and more as a norm (Dean 1999, 188ff.). This is a valuable insight in the case of telecommunications in which (as we noted above) there has been a consolidation and redrafting of key legislation, as well as a shift in law from reliance on statutes and courts to industry self- and co-regulation. Some of the features of this new landscape may be shown in an Australian case, which has its parallels elsewhere.

There have been a number of significant struggles and legal cases worldwide in which access to telecommunications for people with disability has been achieved (World Institute on Disability 1998). A fascinating example of these struggles is *Scott, DPI v. Telstra*, a landmark case that was heard by the Australian Human Rights and Equal Opportunity Commission (HREOC). The case arose when Mr. Scott, a Deaf person from Perth, Western Australia, took an action against Telecom Australia (the national

carrier, now called Telstra) for failing to provide a text phone. Scott was joined in his action by the peak disability movement of the time, Disabled Peoples' International (Australia). The victory in the Scott case was extremely significant in terms of defining telecommunications access in Australia as a human right, and, therefore, establishing a clear legal precedent that helped to enshrine the principles of the Disability Discrimination Act (DDA) in the Telecommunications Act of 1997.

*Scott, DPI v. Telstra* is an example of how disability was governed so that Deaf people (who, in Australia, had largely avoided identifying as “having” a disability) were required to utilize the notion of disability and its regulatory power in order to gain some form of functional access to the telecommunication system. While the ruling by the president of the HREOC is a strong affirmation of human rights, it also served to govern disability in two crucial ways: first, it required the establishment of a special scheme to complement the status quo, rather than change the status quo in ways that would incorporate deviant bodies; second, it promoted a focus upon one form of disability, fostering a “divide and conquer” attitude that has often been taken when medicalized notions of disability are contrasted with each other. Evidence of the pathological body was pivotal to the determination of the case and manifested in the scheme that Telstra established to give effect to the ruling (Bourk 2000).

The broad operation of the regulation of disability is evident in mobile telecommunications, as *Scott, DPI v. Telstra* demonstrated. When the issue of the accessibility of second-generation mobile telephony for hearing-aid users brought public outcry, the matter was managed in a range of quasi-governmental, governmental, and corporate forums; this management brought only a partial and dilatory resolution to the matter. In addition, in Australia at least, the matter required the intervention of the human rights body. The HREOC hearing had the effect of shutting down critiques of the regulatory and technological systems, that is, those systems that operate within the requirements of governmentality. Resistance to the normalizing operation of the law was thus discouraged.

### *Active Citizenship*



The work of Nikolas Rose enables one to elucidate the sense in which one inhabits a society within which power is not centered simply in a state or in transnational corporations. From Rose's governmentality perspective,

power is located in loosely connected arenas and sites in which self-activating citizens are enlisted to play a role in constructing and policing circumscribed zones of autonomy and freedom (Rose 1999). Conceived in this way, power exists in conjunction with an active, sophisticated citizenry; indeed, such a concept of citizenship is constructed in the discourse of competitive telecommunications. Active citizens are expected to do the work of making choice, competition, and new networked technologies possible; that is, they are expected to consume mobile telecommunications in all of its myriad forms: to download special ringing tones from the Internet, to avidly send and receive short text messages, and to eagerly anticipate the advent of video broadband telephony.

The consumer-citizen is expected to be a self-propelling agent engaged in the considerable work that being free to choose involves, as well as to participate in the reworking of governance under the rubric of industry self-regulation. In telecommunications, we find evidence of Rose's gloss on the new ways in which "advanced liberal forms of government" rest upon the "activation of the powers of the citizen."

Citizenship is no longer primarily realized in a relation with the state, or in a single "public sphere," but in a variety of private, corporate and quasi-public practices from working to shopping. The citizen as consumer is to become an active agent in the regulation of professional expertise. Even in politics . . . the citizen is to enact his or her democratic obligations as a form of consumption. (Rose 1999, 166)

People with disabilities and the disability movement are, in a variety of ways, called upon (in Althusserian terms, "interpellated") to be active consumer-citizens. For example, people with disabilities are asked to be involved in the formulation of their own "choices" about the products and services they receive. At another level, they are asked to be involved in the formulation of state and corporate policy and regulation in macro- and microarenas. For example, the introduction of competition in telecommunications worldwide has been accompanied by a rhetoric of "customer focus," calling for consultation with consumers, that is, invited consumer representation on advisory boards or panels. These consultative fora have assumed greater importance because they have taken up some of the regulatory and policy-formulation roles that had previously been governed by the state and its agencies. In Australia, furthermore, an industry self-regulatory body (the Australian Communications Industry Forum) that estab-

lishes regulation in areas that had previously been governed by the state, also extends regulations to new areas of governance. The forum established a specific Disability Advisory Body in order to manage and govern (“consult”) the disability sector, and to keep people with disability at arm’s length on “special committees,” rather than directly represented on the board that ultimately makes decisions. In industry self-regulation, moreover, decision-making bodies have been comprehensively dominated by industrial discourse, which recites the mantra, “Competition is inherently good.” Sadly, this more often than not means that the realities of disability are not represented (Newell 1998a). Thus, we would seriously question the quality and democratic nature of consultative and participatory processes employed in industry self-regulation, as well as the substances of the outcomes that they deliver. In this respect, we share the concerns of the consumer movement about the adequacy of and compliance with co- and self-regulatory codes of practice and standards (see, for example, Campbell 2000). For in order to manage the “problem” of disability, these systems of governmentality marginalize people with disabilities and their representatives, and continue to use consultation techniques that are based on nondisabled norms.

There is, then, a twofold character to disability and governmentality. Like other deviant bodies in society, people with disability are located on the margins of telecommunications. Disability is constituted as an “add-on,” that is, people with disability inherently require “special solutions.” Well-intentioned efforts to understand and address the needs of people with disabilities have created a complex apparatus of practices to manage and govern disability: special equipment funds, special modifications to technology, specific entitlements for people with disabilities, or certain groups of people with disabilities, and separate consultative bodies. Since disability has been finally given some limited recognition in telecommunications, very often representative groups of people with disabilities (and people with disabilities as individual consumers) are expected to play an extremely proactive role in the articulation of the needs and expectations of these people, and thus educate telecommunications companies. Our argument is that if disability shares the trend to “active citizenship” that is of a piece with the contemporary forms of governmentality that Rose identifies, then a specific modality of governmentality exists that relates to the power relations of disability—a modality symbolized by the way that people with disability are overlooked as “active citizens,” lingering on the margins of the governable.<sup>3</sup>

*Government and Beyond*

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As we have suggested, the concept of governmentality is a helpful tool with which to understand the social and cultural shaping of disability in mobile telecommunications, insofar as that concept provides an optic for understanding the ongoing narrowing of norms that are used to construct disability, even in the supposedly “advanced” third and subsequent “generations” of mobile telecommunications. We suggest, nevertheless, that governmentality itself fails to account for a number of crucial aspects of disabling mobile telecommunications. Thus, we wish to propose some challenges to the Foucauldian frame, especially with respect to its ethical dimensions.

One of the fundamental concepts that has emerged from people with disabilities in the global context is a shared experience of oppression. This commonality has been documented and theorized by a variety of disability studies scholars, particularly those who live with disability. While Foucault’s recasting of the central notion of power is undoubtedly a complex and rich one, there is a fundamental sense in which it seeks to critique the notion of oppression. Foucault’s later work evokes the productive, as well as the repressive, nature of power. This insight is helpful; yet the stark realities of living with disability entail an experience of power as direct and unidirectional, rather than indirect and diffuse. To take an example described above, no modification to the technology of mobile phones has been made in order to meet the needs of hearing-aid users, despite documentation that mobile phones cause interference with hearing aids, and despite complaints from hearing-aid users themselves.

Furthermore, lessons about the incorporation of disability into first- and second-generation mobile telecommunications have been scarcely registered in the design and rollout of third-generation (3G) mobile telecommunications. This, then, is an example of how dominant, concentrated centers of power with respect to disability still remain in mobile telecommunications (a crucial social space). It is the case that power is exercised through a diffuse network of microsites; however, people with disabilities experience a remaining oppression that calls out for a theory of power recognizing the enduring, if shifting, power blocs of dominant and marginal groups. This oppression is not necessarily monolithic, nor does it necessarily take any one given form or universal shape. However, we are yet to come across some manifestation of disability that does not involve some forms of oppression by virtue of the power relations that constitute that very disability.

Governmentality is a useful concept for understanding how law, regula-



tion, and practice operate in the telecommunications context, a context in which the relationship between the state and the market has substantially changed. A very active reconstruction of regulation has occurred under the aegis of a rhetoric that suggests otherwise. Most of us have been active participants in a systematic extension of control and surveillance enabled, ironically, by advanced telecommunications technologies that are supposedly liberatory. There are, however, further dimensions to these changes, dimensions whose concomitant implications for disability a governmentality perspective may not adequately comprehend. “Light”-touch regulation, for example, is based on narrow norms that further disable. States have promulgated general legislation in the name of citizens’ rights (for example, via antidiscrimination legislation that perpetuates disability through the definition and regulation of deviant bodies). Another response in some jurisdictions has been to craft “last resort,” or minimum standards, legislation or regulation that is usually invoked only after the industry has demonstrably failed to create and enforce suitable regulation. A central aspect of this environment of the realignment of the roles and responsibilities of states and corporations, and of public and private sectors, is the complexity that this sort of realignment entails. This complexity poses real difficulties for people with disabilities who seek to intervene powerfully into these new arenas of power. Compared to states and corporations, social movements and nongovernmental organizations are at a distinct disadvantage with respect to intervention, due to the time and resources required to attend innumerable committee meetings and public consultations, to analyze documents, and to prepare submissions.

The challenges that disability poses to theories of governmentality are even more profound than this complexity indicates. Contemporary notions of citizenship, including those associated with governmentality, assume ability to access and use a range of communications technologies, as visions of e-government suggest. What, then, of many people with disabilities who are excluded from the communications that they may require in order to be admitted to the ranks of cyber-citizens, as defined by dominant norms? These people are of course active citizens; but do their activities count? When one is a person with multiple speech and communication disabilities for whom the communications system is not viable at all, how is one to participate as an active citizen in the process of governmentality? Uptake of text phone technology has in fact been notoriously low within the speech-impaired community. We would suggest that this “low uptake” is due in part to the fact that the text telephone is a cultural artifact

of the Deaf community, and has been imposed by narrow nondisabled norms upon members of the speech-impaired community, many of whom have multiple physical disabilities. This suggestion bears out Mitchell Dean's observation:

Government, if one likes, has become more multiple, diffuse, facilitative and empowering. It is also, however, strangely more disciplinary, stringent and punitive. The national state takes on less a directive and distributive role and more a coordinative, arbitrary and preventive one. (1999, 171)

As Dean highlights, one of the tensions in theories of governmentality is the emergent division between *active citizens*, who are capable of managing their own "risk," and *targeted populations* (disadvantaged groups, the "at risk," the high risk), who require intervention in the management of "risks" (1999, 167).

A Foucauldian analysis helps us to reframe telecommunications (mobile and otherwise) as a system of power and governmentality, rather than "merely" technology. In the last decade of the twentieth century, the construction of disability in telecommunications finally achieved some recognition; in addition, attempts were made to address the needs and expectations of people with disabilities. This history is often recounted as a story of progress, rather than as a narrative in which power is exercised over time through so-called novel modes of constructing disability and accounting for deviant bodies and minds. In this regard, an understanding of governmentality is especially helpful insofar as it provides tools with which to discern the productive, as well as the repressive, elements of powerful practice in contemporary telecommunications. Nevertheless, disability studies must speak back to theories of governmentality, by highlighting their stark gaps and absences.

In his introduction to the volume that inaugurated the swell of interest in governmentality among English-speaking intellectuals, Colin Gordon hints at a new field of potentiality for politics: "[T]o the extent that the governed are engaged, in their individuality, by the propositions and provisions of government, government makes its own rationality intimately their affair: politics, becomes, in a new sense, answerable to ethics" (1991, 48). This call has not yet been received. We believe it is still worth answering.

## NOTES

1. By “disability” we mean a complex and contested sociopolitical space. As Fulcher (1989) suggests, disability is constituted by discourses. In this chapter, we utilize a social model of disability in order to emphasize the rights of people with disability. We think Albrecht, Seelman, and Bury are correct: “Disability is an enigma that we experience but do not necessarily understand” (2001, 1). There is no doubt that we cover significant intellectual and personal territory in this chapter as we seek to more fully understand the often taken-for-granted contested space referred to as “disability.”

2. Text phones were originally based on the Baudot standard that is used for telex machines, but many now also use the American Standard Communications Information Interchange (ASCII) standard that is used by computer networks.

3. One needs to recognize that people with disabilities are routinely not regarded as full citizens because physical “deficit” is translated into lack of moral worthiness. No better example of this attribution of moral standing can be found than that provided by the lack of discussion of disability as a mainstream political issue in Western societies, in general, and in the recent constitutional convention conducted in Australia with regard to the proposition that the country should become a republic, in particular (see Newell 1998b).

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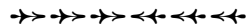
IV



*Ethics and Politics*



JULIE ALLAN



## Inclusion as an Ethical Project

The inclusion of disabled students within mainstream schools continues to be debated amid criticisms of conceptual confusion among those holding opposing views (Gallagher 2001), and accusations that inclusion has become an ideological battlefield (Brantlinger 1997). The reduction of inclusion to a technical matter or problem of resource distribution has deflected attention from the radical changes that teachers must initiate, and that schools require, in order to create the conditions necessary for inclusive education; furthermore, this reductionism has led to a general inertia in which the very idea of inclusion is called into question as possibly too idealistic (Slee 1996, 1998; Barton 1997; Slee and Allan 2001). In this chapter, I seek to break this inertia, by drawing on the ethics that Foucault developed in the much neglected final phase of his work. The chapter presents the inclusion of disabled students in mainstream schools as an ethical project, in which all concerned—disabled students, mainstream students, teachers, and researchers—have responsibilities. The ethical work on our selves and our practices that is required to create the conditions for inclusion is guided by an underlying *telos* and a set of principles that “tell you in each situation, and in some way, spontaneously, how you should behave” (Foucault 1987a, 117). Work of this kind involves challenging “the evidence and the postulates, of shaking habits, ways of acting and thinking, of dispelling commonplace beliefs, [and] of taking a new measure of rules and institutions” (Foucault 1991a, 11–12).

Foucault’s work, attention to which has focused largely on his archaeological and genealogical phases, has been identified by some authors as pessimistic, and claimed to offer little prospect for social change (Shumway 1989; Rorty 1990). In particular, Foucault’s genealogical analyses of disciplinary techniques have been said to portray individuals as unlikely to resist successfully (Žižek 1999). The elaboration of ethics in relation to inclusion goes some way to refute these accusations of pessimism, by specifying the



responsibilities that each of the individuals involved has to remove existing exclusionary pressures. By setting out the work that each of us must do, the ethical project of inclusion also provides a response to Slee's (2001) enjoinder that inclusion starts with ourselves. First, I will elaborate the dimensions of this ethical project—the determination of the ethical substance, the mode of subjection, self-practice or ethical work, and the *telos*—in regard to teaching, teacher education, and research and will in turn exemplify these dimensions. Then, I will offer some suggestions about how disabled students could be helped to undertake inclusion as an ethical project. These suggestions are intended as a mere starting point from which others could begin to determine their own self-knowledge and conduct.

### *Foucault's Ethics and Inclusion*



Inclusion emerged in the educational discourses of the early 1990s, replacing the concept of integration, which had come to be viewed as unsatisfactory (Slee 1993). Integration was problematic because, in practice, it related only to the placement of children with “special educational needs” in mainstream schools, with the goal of increasing their participation alongside their mainstream peers in social and educational activities. By contrast, inclusion starts with the premise that an individual has a *right* to belong to society and its institutions, which therefore implies that others have obligations to ensure that this happens. In particular, inclusion necessitates the removal of barriers that may prevent individuals from belonging. These barriers may deny individuals access to buildings or material or cultural resources, or may convey messages to individuals according to which they do not *really* belong. Removing these barriers implies major structural and attitudinal changes and a fundamental shift away from the deficit-oriented thinking that has for so long driven educational practices.

The ethical project for inclusion that I developed in the late 1990s emerged from research that I undertook with eleven students who have been identified as having *special educational needs* and with mainstream peers of these students (Allan 1999). The accounts that the disabled students provided revealed highly sophisticated forms of transgression against the identities and experiences that their peers, teachers, and parents imposed upon them (see Foucault 1977a). Transgression enabled the disabled students to gain some control over their lives and their relationships with others. The mainstream students, whose accounts demonstrated highly

nuanced understandings of disability, and of the conditions required for justice and equality, revealed how they played a key role as *gatekeepers* of inclusion. This positioning as gatekeepers was understood to operate within a microregime of governmentality (Foucault 1991b, 118), which functioned as a set of unwritten rules of conduct and sanctioned or prohibited certain actions. Furthermore, the mainstream students' microregime of governmentality appeared, for the most part, to support inclusion by, for example, sanctioning strategies that were pastoral or pedagogic in their orientation. Nevertheless, the ambivalence and uncertainties that the mainstream students had (for example, in situations where they felt anxious about or sorry for certain students) were disabling.

Inclusion for the disabled and nondisabled students was not some static, once-and-for-all, event concerned with placement and resources; rather, the students regarded inclusion as a much more unstable, and often playful, process. The research revealed a clash of discourses between, on the one hand, students' own desires and, on the other, the teachers' articulation of the students' needs. Tensions between these competing discourses of desires and needs often arose within the classroom, and these tensions were usually resolved by silencing the students' desires with the voluble professionally based needs discourse. The students' accounts, which contrasted with this professional needs-based discourse, offered a sanguine view of inclusion that did not hold to a utopian "vision"; rather, the students viewed inclusion as the place of "struggle" (Barton 1997, 239), from which inclusion can realistically be achieved, but only if everyone involved in this struggle begins to recognize the exclusionary nature of existing practices. The conception of ethics that Foucault introduced in his later writing offers a promising way in which to frame the work that everyone involved in inclusion must do in order to understand the responsibilities in this regard. Foucault's framework of ethics focuses on "the forms of relations with the self, on the methods and techniques by which he works them out, on the exercises by which he makes of himself an object to be known, and on the practices that enable him to transform his own mode of being" (1987b, 30).

Foucault did not give advice on how one should undertake a transformation of this kind in practice (Smart 1998). He mentions the role of the counselor, the friend, the guide, or master "who will tell you the truth" (Foucault 1987a,) about yourself, but he did not prescribe the nature of the relationships involved. Bernauer suggests that Foucault provides an invitation to others "not to renounce the soul . . . but to transgress its borders, to reinvent one's relationship to it" (1999, xiv). This invitation enables indi-

viduals to see themselves as the main source of transformation, rather than as passive subjects waiting for a more substantial structural or material change. As Veyne observes, “[T]he self is the new strategic possibility” (1997, 231).

Foucault (1987b) regards ethical practice as having four dimensions, which he elaborates in relation to Christianity and sexuality. He points out that the four dimensions of ethics will inevitably overlap and cannot be dissociated from one another, or from the actions that support them.

1. *Determination of the ethical substance.* This dimension involves the identification of “this or that part of oneself as prime material of [one’s] moral conduct” (1987b, 26). Individuals decide which aspect of the self to work on, or to change. In Foucault’s example of Christianity, one’s beliefs, intentions, or desires might be specified as the objects to transform in order that one will become a better Christian.

2. *The mode of subjection.* This ethical dimension concerns the “way in which the individual recognizes how he or she operates in relation to certain rules and to find other ways of observing these rules” (1987b, 26). Foucault illustrates this dimension with the example of fidelity, and contends that there are many ways to practice austerity and “be faithful” (26). The Greek aristocrat who fashions his diet according to certain aesthetic criteria provides one example of the mode of subjection (see Blacker 1998).

3. *Self-practice or ethical work.* This aspect of ethical practice involves what one does “not only in order to bring one’s conduct into compliance with a given rule, but to attempt to transform oneself into the ethical subject of one’s behavior” (Foucault 1987b, 26). Thus, sexual austerity in Foucault’s example can be practiced silently through thought or by a much more explicit and “relentless combat” (26). It is a form of “asceticism” (Blacker 1998, 362) through which individuals transform themselves.

4. *The telos.* The final dimension concerns the ultimate goal that an individual aims to achieve through ethical work. Foucault’s example is fidelity as part of a journey toward complete self-mastery, highlighting the moral aspect of the transformation of self that this journey involves. Blacker describes this process as a kind of “controlled and self-regulated dissemination of the subject into the world, a positive dissolution . . . not self-absorption, but being absorbed into the world: a *losing-finding* of the self” (1998, 362–63).

Foucault argues that one should become so accomplished in ethical practice that one engages in it unconsciously.

You must have learned principles so firmly that when your desires, your appetites or your fears awaken like barking dogs, the *logos* will speak with the voice of a master who silences the dogs by a single command. (1987a, 117)

While Foucault's example of ethical practice is directed toward a kind of sexual austerity, the practice itself can be viewed as a means with which to promote inclusion that recognizes disabled students' desires, in addition to their needs. This work to recognize students' desires and needs is not only ethical; it is also a political, social, and philosophical endeavor that is put into practice through a kind of "curiosity" (Foucault 1988a, 321); it is a practice that

evokes the care of what exists and might exist; a sharpened sense of reality, but one that is never immobilized before it; a readiness to find what surrounds us strange and odd; a certain determination to throw off familiar ways of thought and to look at the same things in a different way . . . a lack of respect for the traditional hierarchies of what is important and fundamental. (321)

Levinas (1987) identifies the challenge that this work poses to individuals as one of responding to, and for, the Other without creating further obligations in the Other. Foucault highlights the necessity of establishing conduct that "seeks the rules of acceptable behavior in relations with others" (1988b, 22), but foregrounds the self as the principle object of care, and as a means through which care for others can occur. Smart (1998) claims that this contemporary version of caring, this caring for oneself, which is characterized by self-determination, self-expression, and hedonism, has in fact led to indifference toward the other; but this need not be the case. In the research that informed the development of inclusion as an ethical project (Allan 1999), the mainstream students portrayed inclusion as good for them, as well as good for the disabled students. The mainstream students witnessed disabled individuals progress in learning and improve their social skills through their inclusion in mainstream classrooms. They perceived themselves as benefiting from inclusion in two ways: first, they felt that they were actually doing something that would contribute to social change; and second, they gained greater respect for their disabled peers.

*The Ethical Project for Academics*

As an academic who is involved in teacher education and disability research, I would like to offer some personal thoughts on how the ethical project of inclusion might be directed to work on the self in the context of both of these activities and in relation to teaching. The four interrelated dimensions of ethics, as applied to inclusion, focus largely on exclusion and attempt to specify how individuals might remove the pressures that exclude disabled students from mainstream schools and classrooms. I do not regard my remarks in this context as a template that others must slavishly follow; rather, these remarks represent my attempt to elucidate, through the conceptual framework of Foucault's ethics, what inclusion requires each of us to do.

*Special Education "Damage"*

The task of determining the ethical substance (the part of ourselves that is to be worked on) has been made easier by the writing of disabled people who have highlighted the damage that the practices of special education have done to them (Barnes 1996; Oliver 1992, 1999). The anger and betrayal that many disabled people feel about educational practices that exclude them and about "tarmac professors and researchers" (Oliver 1999, 191) who colonize their experiences is quite evident in the work of disabled writers. As Oliver states, this exclusion is unacceptable and must not be allowed to continue.

Felman claims that the biggest barrier facing teachers derives from their own "passion for ignorance" (1982, 30).

Teaching . . . has to deal not so much with lack of knowledge as with resistances to knowledge. Ignorance . . . is a *passion* inasmuch as traditional pedagogy postulated a desire for knowledge—an analytically informed pedagogy has to reckon with *the passion for ignorance*. Ignorance, in other words, is nothing other than a desire to ignore. . . . It is not a simple lack of information but the incapacity—or the refusal—to acknowledge one's own implication in the information. (30)

This "passion for ignorance" extends to the education *experts* whose responsibility it is to educate student teachers in special education by providing a series of specialist inputs. Slee denounces the "conservative incrementalism" (2001, 173), that is, very cautious knowledge-production about

students' "deficits," and how to manage them, that exists in current teacher-training. According to Slee, the training of future teachers revolves around the transmission of regulated chunks of *traditional* special educational knowledge, which enables the professionals to retain their authority and ensures that classroom teachers "are not so spooked" (2001, 173) when different students enroll in the classes that they teach.

In many teacher-training establishments, *inclusive education* has provided traditional special educators with a publicly acceptable base from which "the teacher-training imperative" (Slee 2001, 173) can be perpetuated. This reconfiguring of teacher training is done without undertaking the radical reform of pedagogy that inclusion requires; furthermore, this form of teacher-training continues to shape the teacher into a "card carrying designator of disability" (Slee 2001, 171) who is able to identify students by their deficits, but is unable to recognize the kinds of barriers to the students' participation, which teachers themselves help to create through their own teaching practices.

The unwillingness of researchers to address the power relationships within which special education research knowledge is produced has maintained the binary divide between researcher and researched, leading disabled people to view this research as a "violation" and "irrelevant" (Oliver 1992, 105). In recent years, disabled researchers have become more prevalent, and there have been more attempts to take account of the experiences of disabled children and adults; nevertheless, many authors have expressed the view that disability research has failed to understand, or to make any significant differences in, the lives of disabled people (Barnes 1996; Kitchen 2000; Duckett and Pratt 2001). In addition, the failure of many researchers to theorize has done untold damage to the project of inclusion, allowing the project to become no more than "a new language for functionalism" (Slee 1998, 130). Theorizing, as Slee reminds us, is a political activity. As Barnes notes, disabled people have been instrumental in shifting the theoretical analysis of disability "from individuals and their impairments to disabling environments and hostile social attitudes" (1996, 43). In the context of special education, disabled people, who have been the recipients of this institutional practice, are marginalized from the research and knowledge that is produced about it, by virtue of an unwillingness on the part of nondisabled researchers to alter the objectifying relations of power that condition their work and enable them to maintain their control over disabled people (Oliver 1992).

In his "final accounts" as a disability researcher, Oliver describes his "pain and disillusionment" about the way in which disability research has

failed disabled people (1999, 183–85). Oliver’s valedictory documents how research accounts of the experience of disability, which have been produced by those who are “parasitic upon disabled people” (184), are part of a discourse that prioritizes investigation over emancipation. In closing his “own research account” (185), therefore, Oliver calls for an engagement by non-disabled or “tarmac” (191) academics with research that is based on what he calls a “discourse of production” (189), that is, a means of subjecting to critique the very knowledge that is produced within research relationships.

Scrutiny of the ways in which closure in “special needs” thinking disables, and of the way that so-called truths about integration and inclusion have been “manufactured and disseminated” (Blacker 1998, 357), is an important task for academics. Smart suggests that what is needed is a “critical examination of the various ways in which we have come to govern ourselves and others through the articulation of a distinction between truth and falsity” (1986, 171). Smart suggests, furthermore, that this examination requires attention to the process of knowledge production. Determination of the ethical substance, with respect to inclusion, requires academics who write about inclusion to acknowledge their complicity in the creation of exclusionary pressures. As Blacker insists, critiquing one’s own work in this way does not entail searching for the *truth* about oneself, but rather requires “attentiveness to how one’s actions get absorbed by the power/knowledge regime” (Blacker 1998, 360).

### *The “Cultural Vigilante”*

The task of identifying the mode of subjection that governs the academic should be considered as a quest to expose exclusion within our institutions and practices, as the actions of a kind of “cultural vigilante” (Corbett and Slee 2000, 134). To pursue a mode of subjection in relation to inclusive educational practice, the academic might attempt to unravel the existing misconceptions about inclusion and problematize what is known about special education by questioning the so-called scientific foundations of our knowledge (Gallagher 1998). Ideology, which has been used as a weapon by special educators in order to denounce those who promote inclusion (Brantlinger 1997), must be scrutinized. Although Foucault argued that the epistemological assumptions on which the concept of ideology relies made it unhelpful, there is a definite need to examine how ideology is strategically employed within the heated debates about inclusion. A critique of knowledge and of ideology should be undertaken with an attitude of suspicion,

which Foucault himself (1983) argues is more productive than the hopelessness and despair with which he has been charged. An attitude of suspicion allows us to question why things exist as they do and to adopt a “hyper- and pessimistic activism” (Foucault 1984, 343) in which we have “an ethico-political choice to make everyday [in order to] to determine which is the main danger” (343). The *cultural vigilante* is a political animal whose frankness will be unattractive to academics and nonacademics in positions of authority. Thus, exclusion, isolation, or other negative repercussions in the academic sphere may be the consequences of engaging in this form of critical activity. Solidarity with, and support for, those individuals who pay the price of speaking out may be one way in which the academy can function positively and creatively.

### *Losing the Authority to Speak*

There have been many calls for scrutiny of professional knowledge (see, for example, Skrtic 1995; Tomlinson 1996) and of the interests and investments that teachers have in the knowledge that is forged within research and educational contexts (Orner 1998). Skrtic (1995) argues that the process of professionalization creates individuals who, on the basis of knowledge that they assume to be objective, share the belief that they are acting in the best interests of clients. The key activities of self-practice or ethical work are deconstruction, criticism, and reflexivity, all of which will help to undermine or subvert the “ideology of expertism” (Troyna and Vincent 1996, 142).

Lowson (1994) offers a useful reconstructive strategy in this respect by inviting professionals to pathologize themselves as suffering from Professional Thought Disorder (PTD). This condition has a number of features, including a compulsion to analyze and categorize the experience of others; disordered cognition, which manifests itself in rigidly held beliefs; delusions of grandeur; and negative transference and projection, in which sufferers cannot distinguish their own wishes and impulses from those of the people whom they wish to help. When professional language is turned back toward the professionals themselves, the effect is “distinctly sinister” (Lowson, cited in Corbett 1996, 40). However, if teachers were to scrutinize their own “clinical symptoms,” as a staff development activity, for example, they might be encouraged to recognize and remove the “rigidity, imperviousness and defensiveness” (Lowson, cited in Corbett 1996, 40) in their language and practices. In addition, this kind of staff development activity might help disabled students (and others), who are forced to endure dis-



abling experiences, to understand the etiology of PTSD and to recognize its symptoms.

Deconstruction of key policy texts in teacher education will help to reveal the ways in which these texts “get into trouble, come unstuck, offer to contradict themselves” (Eagleton 1983, 134). Deconstruction is intended to operate as playful, positive, and generative. Derrida explains that “it’s not a question of calling for the destruction of such institutions, but rather of making us aware of what we are in fact doing when we are subscribing to this or that institutional way of reading” (1984, 125). Citing Baudrillard (1984), Oliver dismisses this “pessimistic postmodernist approach to life as survival amongst the ruins,” viewing it as part of the “sociological drift to irrelevance” (1999, 190). However, deconstruction’s relevance is that it disrupts the “decidability” (Patrick 1996, 141) of key texts, and exposes the exclusionary pressures that continue to be inscribed within them (Slee and Allan 2001). Deconstruction does not function, as Giroux (1988) and McLaren (1995) contend, as a prelude to reconstruction; such a futile gesture would only recreate dividing practices. Deconstruction enables individuals to engage in a more profound kind of learning about themselves through which they come to “know what they do; . . . know why they do what they do; . . . [and] know what they do does” (Foucault, cited in Dreyfus and Rabinow 1982, 187). This practice is far from being an exercise in gloom, since Foucault’s point is not that “everything is bad, but that everything is dangerous. . . . If everything is dangerous, then we always have something to do” (1984, 343).

The practice of criticism, of “making facile gestures difficult” (Ransom 1997, 100), can be undertaken in the context of both teacher education and research. A key feature of the practice of criticism is the production of writing and research that must “be *responded* to rather than just read” (Stronach and Maclure 1997, 158), and that creates openings for debate, rather than closures through certainty. Academics might also make themselves more available for criticism from colleagues, by engaging in “experiment, creativity and risk” (152). An exciting exemplar of the practice of criticism can be found in disability arts (Allan 2004). Through playful and disruptive boundary work, and its subversion of the “normality genre” (Darke 1998, 184), disability arts functions as a highly effective form of ideological critique. The exposure of a deeply complacent and suspicious education community to this work is vital in order to guide its members in the practice of criticism and to help them recognize the disabling consequences of their own “facile gestures.” Furthermore, reflexivity, which is the process of scrutinizing one’s own thoughts and

actions, should help to expose, and subsequently remove, exclusionary practices, and to reveal those “passions which interfere with reason” (Darke 1998, 135). We must also examine the stories that we tell ourselves and the way in which we justify them, undertaking, in effect, “a kind of confession to ourselves” (Foucault 1999, 166). Ransom cautions that we must not view reflexivity as a solitary form of subjectivity or as a “narcissistic flight from *real politics*” (Ransom 1997, 156; emphasis in the original). On the contrary, reflexivity is a political activity that foregrounds what we think, say, and do as the material for transformation.

### *Inclusion: Not Yet There?*



Identification of the *telos* (the overall goal of ethical practice) is the most difficult of the four dimensions to accomplish, principally because of the way in which we mythologize our sense of progress toward full inclusion. Our conviction that we are *not yet there* with regard to indicators and outcomes within the quality assurance genre has extended to inclusion; however, these indices have not encompassed the views of disabled youngsters and their parents regarding what the desirable consequences of inclusion should be. Indeed, indicators of the quality assurance imperative have been limited to a specification of increases in the number of children present in mainstream schools (DfEE 1997) or reduction in the numbers of children who have been formally assessed as having special educational needs (Scottish Executive 1999). In short, those of us who are engaged in inclusive education have not yet addressed the major teleological questions, which are: What do we want inclusion to do? And how will we know if we have succeeded at it?

### *Helping Disabled Students to Transgress*



If mainstream students, teachers, schools, and researchers undertook inclusion as an ethical project, much of the oppression that disabled students normally experience in schools would be removed. Within the scope of inclusion as an ethical project, disabled students can be helped to manage the disabling situations in which they find themselves and to find ways in which to tackle the disabling barriers that they encounter. Furthermore, nondisabled students could be encouraged to undertake inclusion as an ethical project on themselves, which could produce lives that

are “larger, more active, more affirmative and richer in possibilities” (Deleuze 1988, 92).

Disabled students may need some encouragement to explore the possible ways of being active subjects with options for transgression. Practices of transgression, in the context of inclusion, differ from antagonistic or confrontational styles of resistance; they represent a more agonistic form of struggle against those who attempt to exclude. Transgression could, on the one hand, be seen as representing a restricted level of engagement for disabled people; on the other hand, however, transgression could signal opportunities for practical involvement in battles that can be won. Students could be helped to explore their sense of self—expressed as desires rather than needs—and to analyze the diverse factors that enable or constrain them. This exploration could in turn lead to the removal of some constraints, and to the enunciation of strategies with which to circumvent other ones. Teachers could specify the kind of support that particular students need, with the teacher and a given student exploring the consequences of receiving this kind of support, or of doing without it. By negotiating with students various ways in which to provide support within classrooms that do not interfere with peer interaction, nor reinforce students’ sense of difference, teachers may learn to recognize students’ needs and desires simultaneously. Furthermore, dialogue of this kind may encourage students to “escape the grasp of categories” (Foucault 1977b, 190) and to practice alternative forms of conduct. The point of this exercise would not be to abolish the identities (or subjectivities) of students; rather, the intention of the exercise would be to transform the way in which they experience those identities (Simons 1995). The ethical project for disabled students privileges their own desires over needs that professionals have constructed for them. This work also recognizes that knowledge about the *special needs* of disabled students is an instrument of power that constrains and disables them. While there is much work that disabled individuals might do in order to tackle these constraints (such as helping their mainstream peers to understand how they prefer to be treated), other limits may be more intractable. Greater knowledge of the ways that a disabling society constructs these limits may move disabled students toward collective transgressions, rather than individual ones; nevertheless, these kinds of choices should be available to them. Helping disabled students develop transgressive practices that relate specifically to them could reconstitute them as different, and as *in need*; this need not be the case, however, if everyone is recognized as engaged in ethical work on themselves, that is, on their “fragile *shaggy* hybridic identities” (McRobbie 1994, 192; emphasis in the original).

*Inclusion Starts with Ourselves*

The ethical project of inclusion does three important things. First, the project forces us to see inclusion not as something that we do to a discrete population of children, but rather as something we must do to ourselves. Second, the ethical project allows us to “experience ourselves as animated” (Bernauer 1999, xiii), as capable of finding “new secrets, possible freedoms, and inventions that take us in unexpected directions and breathe life back into the human project” (Ransom 1997, 178). Finally, the project allows us to be optimistic about what we can change, which, Foucault suggests, “is to place at the disposal of the work that we do on ourselves the greatest possible share of what is presented to us as inaccessible” (1988a, 156). Foucault recognizes in this optimism a kind of spirituality that provides a “political circle which introduces in your hopes, and through your hopes, the things you want to avoid by these hopes” (1983, 11). The success of the ethical project of inclusion will depend on how far all of the people involved allow themselves to hope, accept their responsibilities, and are prepared to do the necessary work, which starts, of course, with oneself. Butler suggests that by exercising this desire for something other than the status quo, we might find the “prevailing conditions of existence threatened” (1997, 29). She argues that this risk is necessary, however, in order to “expose and open to transformation the hold of social power on the conditions of life’s persistence[,] . . . to begin to imagine the contingency of that organization and performatively reconfigure the contours of the conditions of life” (29).

Reframing inclusion as an ethical project takes us into a politics of desire in which “the only possible way to undertake this process is to actually be attracted to change, to *want* it, the way one wants a lover—in the flesh” (Braidotti 1997, 70; emphasis in the original). When inclusion is reframed as an ethical project that leads to a politics of desire, *special educational needs* becomes identified as “the main danger” (Foucault 1984, 343) to disabled people and as an inappropriate basis for pedagogy. No doubt, the very notion of schools as places where desires are played out will provoke laughter and disbelief in some quarters; tackling these reactions, however, will be part of the work that must be done in the ethical project, not as a kind of evangelism, but rather as a process of learning “how to respond to others . . . how to *go on* with them in practice” (Shotter 1997, 353). In sum, the ethical project of inclusion is driven by desire. Since we can never fully satisfy desire, the ethical project of inclusion will inevitably remain a *work in progress*.

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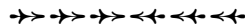
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KATHRYN PAULY MORGAN



## Gender Police

. . . the standard types of arguments designed to show the necessity of human sexual polarization into masculine and feminine fail. While it *is* reasonable to maintain that human beings are essentially sexual, it is *not* reasonable to hold that this sexuality is necessarily either masculine or feminine.<sup>1</sup>

*INSTRUCTION: Press the TRUE STORY Key*



In the early 1990s, a letter arrived at my son's nonsexist day care. It was from the good Dr. Zucker, a psychiatrist and leading gender identity theorist at the Centre for Addiction and Mental Health (a curious name!) at the University of Toronto. In the letter, Dr. Zucker invited us as parents to volunteer our sons to participate in a normal control group of boys relative to a group of gender dysphoric boys who had been diagnosed with gender identity disorders. In his published work, Zucker and his colleagues assess boys according to this scale: attractive, beautiful, handsome, cute, and pretty. The researchers also maintain that by scrutinizing the faces of living children, as well as those presented in photographs, they can identify "pre-feminine boys" and "pre-masculine girls," an identification process to which they give considerable urgency (Burke 1996, 171–74). Since my son had already been "corrupted" by systemic socialization into nonheterosexist practices, beliefs, and values, it was not entirely clear to me that it would have been safe to offer him up as a "normal" (presumably gender euphoric) boy. So, I declined the invitation. Upon reflection, I realized that I had caught a glimpse of the official Gender Police at work, enthusiastically policing the Gender Border.

*INSTRUCTION: Press the GENDER UTOPIA Key*

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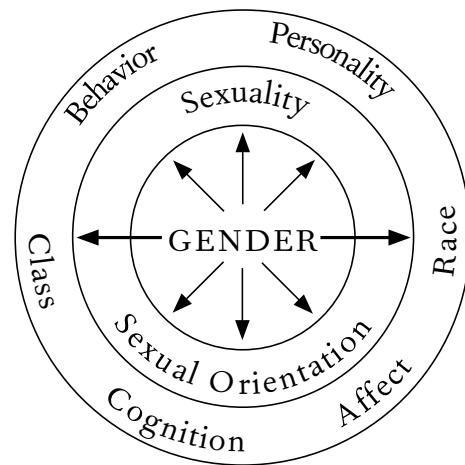
*Enter the Land of Gender DiMorph Utopia!*

In the Land of Gender DiMorph Utopia (GDU) the principle of assigning all human beings to one of two polarized (i.e., dimorphic and mutually exclusive) gender groups is the ruling principle of social organization. This dimorphic gender assignment of individuals is based on the belief that innate gender identity is genitally signified and holds constant for one's entire life (see Kessler and McKenna 1978; Zita 1998). Thus, young members of GDU culture are referred to as either "boys" or as "girls," while adult members of the culture are referred to as either "men" or "women." These dimorphic genders are systematically naturalized by people in GDU who habitually repeat the mantra: "Men are from Mars; women are from Venus." In GDU, furthermore, every dimorphic gender difference (whether in personality, cognition, emotional life, patterns of communication, sexuality, or any other personal dimension) is routinely attributed to fixed, hormonally induced prenatal experiences in which the developing fetus is perinatally "pinked" or perinatally "blued."<sup>2</sup>

Because Gender DiMorph Utopia is a heteronormative society, each of its members must treat everyone else as if he or she were an honorary heterosexual.<sup>3</sup> When nonheterosexual attractions and affiliations must be spoken about, only the language of "same sex: male/male or female/female" dimorphic categories may be used. Use of the word *queer* is forbidden; indeed, its use violates the most profoundly respected rules of linguistic etiquette and is, therefore, punishable by law.

As young as possible, all of the members of GDU learn the significance of the utopian Gender Border emblem that, having replaced outmoded nationalistic flags, is widely replicated throughout the culture in institutional settings such as schools, hospitals, and transportation sites, as well as every private or public sector place of employment. The emblem appears on billboards, is used as a logo on all commodities and official documents, and is the icon that identifies GDU's Internet service provider.

*The Gender Border Emblem and the Ten Principles of Gender DiMorph Utopia* In GDU, normal boys and men are required to carry blue electronic "gender smart cards" that identify them as boys and men; normal girls and women in GDU carry pink electronic "smart cards." These smart cards may be used for gender validation or to prevent gender fraud (such as



the gender crimes that might occur in prestigious athletic competitions). For purposes of surveillance, a specific gender-at-birth microchip is implanted in individuals deemed to be in some way gender-disabled or simply at risk of future gender disablement.

In Gender DiMorph Utopia, everyone recognizes and honors the Gender Border that defines gender dimorphism.<sup>4</sup> In GDU, “the Border” is understood by all as the fundamental basis of societal order, security, prediction, and the prevention of harm. Since dimorphically defined (and *only* dimorphically defined) gender identities are acknowledged as the carnal and psychological integrating principle for normal, healthy persons, protecting the Border is believed to have the highest individual, cultural, and political priority. Producing gender euphoric individuals who voluntarily reinscribe gender dimorphism in their day-to-day lives and long-term dreams and aspirations in a totalizing way is, therefore, a major responsibility for the entire community. Another major responsibility of individuals, families, friends, public institutions, and the community at large is the prevention, identification, and rehabilitation of gender disability in children, adolescents, and adults. Thus, vigilant official Gender Border Police and civilian Neighborhood Gender Watchers play a crucial role in preserving the health and quality of life in Gender DiMorph Utopia (Garber 1992).

The gender dimorphic utopians pride themselves on their enlightened, modern view of gender science and correlative benevolent approach to gender-disabled individuals (Pauly 1992; Steiner 1985; Stermac 1990). These epistemological and ethical stances flow from the GDUtopians’ enthusiastic endorsement of the Ten Principles of the GDU Social Contract, which are:

1. Gendered identity is the core truth of the individual that, in a gender-abled individual, expresses itself in a consistent, lifelong sex-dimorphic way.
2. Maximum attention must be directed to the recognition and study of gender disabilities that cause deviant gender behavior, desires, and forms of self-identification.
3. Each and every member of the community, however, young or old, must engage in surveillance of gender-disabled children, adolescents, and adults so that these people can be rehabilitated into the gender euphoric and productive individuals that they really want to be and that society desires.
4. Since childhood gender disabilities and gender dysphoria often act as precursors to more serious adult-onset, full-blown gender disorders and dangerous gender pathologies, all parents, siblings, relatives, children, nursery and kindergarten teachers, neighbors, and toy store clerks (particularly in outlets of the large chain stores Toys “Я” Boys and Toys “Я” Girls) bear high levels of responsibility for policing children for gender disabilities. In addition, specially trained teenagers and adults—called the “*Kinder* Police”—will serve the community in this policing role.
5. Secular scientific investigation—especially the research that geneticists, psychoendocrinologists, and evolutionary psychologists conduct—provides the best means by which to arrive at an understanding of the biological foundation of normal dimorphic gender identity and the possible forms of gender disability.
6. To maximize individual well-being and societal stability, diagnostic and interventionist technologies should be used—prenatally and postnatally—in order to eradicate genetically and/or hormonally gender-disabled fetuses. All gender ambiguous babies (i.e., babies with ambiguous genitalia) are to be labeled “temporarily intersexed”<sup>5</sup> and surgically corrected as soon after birth as possible so that they may fit into their proper gender location. All requests for gender-related research in fetal endocrinology, fetal surgery, and plastic genital surgery should receive full funding. Innovations in these vital areas of research should receive the wide public recognition and esteemed awards that they deserve.
7. Gender disabilities, which usually manifest themselves as forms of psychopathology, are best treated by psychiatrists with age-

appropriate comprehensive models of treatment. The fifth edition of *The Diagnostic and Statistical Manual of Gender Disabilities* is the canonical text to use for the diagnosis and rehabilitation of gender-disabled individuals (such as gender dysphorics, gender deviants, unstable androgynes, and gender indeterminates). The *Manual* should also serve as a guide for billing purposes. Therapeutic interventions must comply with the revised *Standards of Care of Gender Identity Disorders*, which represent an international consensus about the “psychiatric, psychologic, medical, and surgical management of gender identity disorders” (Benjamin 2001; Cromwell 1999; Ettner 1999).

8. Gender Border crossing is to be permitted (in the few cases where gender rehabilitation fails) if and only if a given gender-disabled individual passes an extensive “Real Life Gender DiMorphism Test” (see Clemmensen 1990). Gender Border crossers and their respective relational communities must be made to understand the psychoemotional and societal importance of gender passing and Gender Border crossing secrecy to the well-being of the community (Kessler and McKenna 1978; Shapiro 1991). All border crossers are expected to acknowledge their economic responsibilities to the community, to contribute as productive members of the community, and to endorse the Ten Principles wholeheartedly in order to conserve the integrity of GDU.
9. In order to safeguard the fundamental principle of gender dimorphism, border crossers must be conceptualized either as “males to females” (MTF border crossers) or as “females to males” (FTM border crossers). Other ways of identifying border crossers should be regarded as unintelligible and punishable by law.
10. All central social institutions (that is, the law, science, the public and private economic sectors, religion, culture, insurance, education, health care, the judiciary, the human service sector) should be integrated in ways that maximize gender-dimorphic subjectivity in order that individuals in GDU can happily express their gender dimorphic personal identity, augment this identity through an integrated variety of gender-polarized cultural and institutional means, and celebrate gender dimorphism as the ideal of the society (see Hucker 1985).

People in Gender DiMorph Utopia take pride in striving to live according to the Ten Principles. Children are extensively socialized into their

gendered identities. Kindergarten teachers can receive national recognition for their innovative gender-dimorphic classroom practices. One of these model teachers invented prizes for the Very Best Thinker, Most Eager Learner, Most Imaginative, Mr. Personality, and Hardest Worker, which boys—and only boys—are eligible to win. In this teacher’s class, girls—and only girls—are eligible to win prizes as All-Around Sweetheart, Sweetest Personality, Cutest Personality, Best Manners, and Best Helper.<sup>6</sup>

In addition to all of the happy gender-dimorphic stories, movies, video games, fairy tales, and make-believe role-playing that the children receive and participate in, certain gender motivational stories have iconic standing in the culture. For example, all children in GDU know “The Story of Michael.” Michael is a gender-disabled boy who overcame his desire to play with jewelry, necklaces, rings, earrings, baby dolls, and Barbie dolls, and acquired a consistent desire to play with dart guns, targets, knives, plastic handcuffs, and action figures of cowboys and male Indians. Children learn how scientists and helpful psychiatrists watched Michael through one-way mirrors and instructed his mother to ignore him if he was expressing his disability through the selection of feminine toys, feminine behaviors, and feminine role-playing. All of the children in GDU know that at Michael’s home the gender experts organized a systematic reinforcement schedule in which physical punishment—which involved spanking by Michael’s father—proved to be the most therapeutically valuable behavior in the rehabilitation of Michael’s gender disability (see Burke 1996, 39ff.).

In GDU, all pre-teens and teenagers read the stories of Daphne, Leslie, and Ladelle, teenagers who were diagnosed with the dual disabilities of gender identity disorder and oppositional defiant disorder. Preteens and teenagers in GDU know that gender disabilities can be dangerous. And they know that’s why it is important for teenagers like Daphne, Leslie, and Ladelle to be hospitalized in gender-healing hospitals for a long time. Furthermore, youth in GDU learn that because this “double disability” can be very difficult to treat, Daphne, Leslie, Ladelle, and other teenagers may need to be drugged with very strong psychiatric medications, experience electroshock, be micromanaged through surveillance schedules, and may even need to spend one to two years isolated from the rest of the world (Burke 1996; Feinberg 1993; Scholinski 1997; McWhorter 1999).

The Gender DiMorphians widely support the gender-healing hospitals because their scientists estimate that as many as 5 to 10 percent of the entire community suffer from gender disabilities. Pamphlets that offer informa-

tion about the healing hospitals are sent to the parents of all teenagers, to the principals of the middle and secondary schools, to the music stores and kiosks at cinemas, to information racks, and to all birth-control clinics for teenagers. Because insurance companies routinely pay the costs of the gender-healing hospitals, all concerned dimorphic parents are financially able to send their teenagers to these hospitals upon the recommendation of their trusted family psychiatrist.

Adult women in Gender DiMorph Utopia who are identified as gender disabled draw inspiration from “The Story of Susan.” Susan was at one time diagnosed with five different, yet simultaneous, gender disabilities: dysthymic disorder, sexual aversion disorder, mild sexual masochism, sexual disorder not otherwise specified (which involved feelings of inadequacy about her femininity), and other borderline traits. In this story, Susan did not feel like a pretty child and always compared herself to her older, pretty, feminine sister. In addition, Susan wasn’t terribly good at being a tomboy. Her failure to realize femininity to its full extent, and in a euphoric way, had affected her liking for herself as a woman. After receiving the Comprehensive Treatment for Gender Disabilities, as well as extensive gender rehabilitation, Susan was completely cured of all of her gender disabilities. She no longer experiences gender dysphoria. Today, Susan is a happy woman, very feminine in appearance, who experiments with dresses, makeup, and hair permanents and takes pride in her embroidery projects. Susan’s gender therapists regard her interest in giving birth to a daughter as the most significant sign of this rehabilitation.<sup>7</sup>

The stories of Michael, Daphne, Leslie, and Susan remind everyone in Gender DiMorph Utopia of the importance of the embodied expression of gender. Normal members of the community are expected to display their dimorphism through specifically gendered speech patterns, norms of appearance, facial and bodily hair, eating and drinking patterns and preferences, degree and kind of muscularity, their hands and fingernails, their preferred movement modalities, their postures, their odors and scents, their height and body size, their erotic assertiveness or coyness, their vocabulary, their modes of cognition, and through the kinds and degrees of their emotional expressiveness.<sup>8</sup> In addition, they are expected to enact their respective dimorphic identities whenever they choose gender-specific public rooms designed for excretory purposes. Documentary display of dimorphism is, of course, compulsory on all public forms and legal documents such as passports, driver’s licenses, and census forms, as well as employment applications, and financial forms.

### *Role of the Central Institutions*

*Universities* While all of the central institutions in Gender DiMorph Utopia are committed to the Ten Principles, its universities play a particularly pivotal role in supporting gender dimorphism. In psychology, the leading gender research journal—the *Journal of Gender Differences*—publishes only research findings that demonstrate the reality of gender differences that are conceptualized in dimorphic terms. A research result of gender sameness is regarded as evidence of faulty research design and methodology and is, therefore, peer-assessed as “not worthy of publication.” Generous funding is provided for all psychological and psychiatric research whose purpose is the identification of prenatal and postnatal risk factors for gender disabilities and their prevention.

Social scientists in anthropology and sociology have an essential role in explaining how the nondimorphic or gender multimorphic practices of other cultures such as Native Americans, the *mahu* in Hawaii, the *hirjas* in India, or normalized cross-dressers in Burma can be cited as evidence of the superiority of gender dimorphism as a civilizing principle of societal organization (see Herdt 1994; Kessler and McKenna 1978; Nanda 2000; Shapiro 1991). For example, these social scientists point out how latent dimorphism is in fact present in these cultures, as the use of notions such as “two-spirited,” “bi-gendered,” or “andro-gyn-ous” within these cultural contexts shows (Morgan 1982).

Social-medical historians also play an important role in the construction of the Enlightenment history of Gender DiMorph Utopia. During earlier periods, when people did not understand how there could be biomedicalized gender disabilities, gender-disabled persons were persecuted, shamed, silenced, abhorred, feared, and criminalized because of the anger, fear, disgust, loathing, panic, anxiety, and hatred that many people felt toward them (Abberley 1987; Zita 1998; Tremain 1996a). Wise psychiatrists recognized that these sorts of homophobic responses stemmed from failure to understand the nature of biomedical gender disabilities (Oudshoorn 1994; Terry 1995; Fausto-Sterling 2000). Today members of the GDU community understand the concept of gender disabilities and acknowledge the pain that is at the center of the lives of gender-disabled persons. They expect, too, that the search for a definitive biomedicalized etiology of gender disabilities will come to a successful conclusion as theories of (for example) prenatal and postnatal neuronal genesis and migration and synaptic pruning become accepted. Earlier practices such as violent persecution and criminalization



have, in principle, been replaced by the enlightened and benevolent policing and therapeutic practices of the GDUPA—that is, the Gender DiMorph Utopia Psychiatric Association (see Morgan 1998a, 1998b).

In GDU, all of the funded research in the life sciences begins with naturalized assumptions of normal gender polarity in humans and foundational sex polarity in nonhumans (Spanier 1995). In the sex and health sciences, the biomedical androcentrism that was assumed in the past has been replaced by a more innovative model in which the two genders are polarized and medical practice is gender-specific (Foucault 1978, 1980a; Laqueur 1990; Schiebinger 1989). Pharmaceutical firms, which market their products in the form of gender-specific pharmaceuticals, lend support to this new model of medical practice and enable dimorphic consumers to express their dimorphism through the gendered health-care commodities that they choose.

### *Gender Policing and Enforcement Agencies*

In Gender DiMorph Utopia, an elaborate family court system has been set up to protect children from parents, relatives, or friends who might try to interfere with, or undermine, their appropriate gender dimorphic upbringing. Family and marriage laws guarantee that no border crossers may marry or be involved in the bearing, adoption, or rearing of children. Because of their legal access to private family settings, special gender-trained social workers support the legislators and the judicial authorities by carrying out extensive gender-policing surveillance in families on behalf of the Utopia.

Although a societal preventative approach to gender violence is promoted, Gender DiMorphians know that gender-disabled persons can sometimes be dangerous and pose a risk to themselves and to the community at large. Criminologists have shown that “examining criminal behavior in gender-dysphoric samples has found criminal activity of some kind well in excess of the general population” (Dickey 1990, 193). In recognition of this finding, the lawmakers of GDU wisely decided to establish a director to head up a Department of Homeland Gender Security. The director is legally empowered to fight, eliminate, incarcerate, or suppress individuals whom the gender police identify as gender subversives relative to the Ten Principles. The Department of Homeland Gender Security works closely with the TechnoGender Laboratory. Receiving generous community and institutional funding, the laboratory has developed gender surveillance technologies such as the implantable gender identity

microchips and deep-brain stimulation gender aversion probes that are used in gender-healing hospitals and in outpatient gender rehabilitation institutes.

The Gender DiMorphians believe that their law enforcement practices combine what is best about risk societies and carceral societies.<sup>9</sup> Through the combined efforts of the gender experts and the gender police, Gender DiMorphians hope to use their knowledge regarding the precursor risk factors of full-blown gender disabilities in order to prevent them altogether. Failing that, Gender DiMorphians are committed to entirely eradicating gender dysphoria and its associated gender comorbidities through preventative, carceral, and rehabilitative practices.

*INSTRUCTION: Press the GENDER UNREST Key*

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Despite the commitment of individuals, families, the community, and its major institutions to the Ten Principles of the Social Contract, the land of Gender DiMorph Utopia is in a state of unrest. Throughout the land, shocking events are taking place:

- > There are individuals who publicly identify as gender subversives, gender outlaws, and transgender warriors.
- > There are individuals who publicly identify as fluidly gendered subjects, as liminal subjects who position themselves right on the Gender Border, and individuals who, through surgical and hormonal means, are creating multigendered nondimorphic bodies.
- > There are gender nomads who openly transgress the Gender Border.
- > There are gender-euphoric hermaphrodites with “attitude.”

According to the GDU Psychiatric Association’s scheme of classification, all of these individuals suffer from gender delusional states and should be diagnosed with severe forms of gender dysphoria. The association formulated this classification and diagnosis because individuals of this nature (along with the disturbed subversive theorizers within the culture and universities who collude with them)<sup>10</sup> deny that the category of gender disability applies to them.

Given the expectation of higher levels of criminal activity and possible gender terrorism among “gender subversives,” the Department of Home-

land Gender Security has issued a Code Lavender (High) in order to alert the public to impending danger. Committed Gender DiMorphians who realize the significance of the threat are, once again, resorting to personal, vigilante, and institutionally mediated forms of violent social control. Gender policing across all personal and public domains has intensified. In Gender DiMorph Utopia, the Gender Border must be protected at all costs.

*INSTRUCTION: Press the FOUCAULT Key*



This chapter is about gender policing in normatively gender-dimorphic societies. I use a Foucauldian theoretical frame to render this gender policing visible and intelligible.

What we can see operating in Gender DiMorph Utopia and other heteronormative gender-dimorphic societies is an “Apparatus of Gender.” Foucault privileges the notion of *apparatus*. So do I. In the conversation “The Confession of the Flesh,” Foucault describes the *elements of an apparatus* as “a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions” (1980b, 194). The elements that comprise an apparatus involve complex, diffuse, and dynamically shifting connections that are, simultaneously, functionally overdetermined through resonance and contradiction and materialized through strategic discursive and nondiscursive elaborations. In Gender DiMorph Utopia, as well as in other secular heteronormative gender-dimorphic cultures, naturalized gender dimorphism functions as just this sort of apparatus.

An *episteme* dwells at the heart of an apparatus. As the discursive heart of any apparatus, the episteme defines the limits and the modes of production of legitimate knowledges, designates those who will be powerfully located as epistemic subjects and producers of legitimate knowledges, and generates strategies of relations of force that sustain the politics of the episteme (Foucault 1980b 197). Since relations of power are constitutively diffused throughout any social body, dominant discourses or epistemes are necessary. For Foucault, it is critical to understand how the epistemes are produced, circulated, and function, since they are central to comprehending how what is regarded as truth is produced through the convoluted workings of power.

Thus, to understand the political constitution of gender disability discourses, it is necessary to scrutinize the episteme of gender dimorphism at

work. Scrutinizing the episteme enables the analysis of the dominance of paradigms of biomedical knowledge, the conflation of discourses on madness and sexuality, the individualizing and reductionistic discourses of disability, the naturalization of gender dimorphic research and clinical knowledge, and the psychocriminalization of the claims to knowledge of “gender deviant” subjects (Foucault 1965, 1973, 1978, 1980a; McNamara 1996). Published by the American Psychiatric Association, *The Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (*DSM-IV*) is the emblematic and powerful point at which gender disability discourses intersect; however, a vast international network of institutions and practices dominated by “gender experts” sustains the episteme of the Apparatus of Gender (American Psychiatric Association 1994; Foucault 1973, 30–31).

Foucault points out that *mechanisms* can range from macropolitical to intimately micropolitical in nature. Identifying, contextualizing, and understanding the institutionally mediated mechanisms that render the diffuse micropolitics of day-to-day life intelligible and complex are, for Foucault, the key to understanding power relations (1980c, 99). Foucault regards mechanisms, which are implemented through various technologies of production, as dynamic points of intersection for the production, transformation, and manipulation of things and individuals; and he connects them to the rise of disciplinary practices and the need to develop panoptimized hierarchical practices of surveillance.

In Gender DiMorph Utopia and other cultures with high levels of compulsory gendered dimorphism, both macro- and micromechanisms of the gender apparatus are integral to virtually all dimensions of civil, social, personal, and gender/erotic life. In other words, micro- and macromechanisms are central to the effective practice of gender government as they engage both technologies of power and technologies of the gendered self. Totalizing regimes of power are, simultaneously, the actuality of individual subjects engaging in gendered self-constituting practices that embody these regimes. With respect to gender governmentality, the goal is a vigilant community of disciplined, euphorically docile, gender dimorphic “normal” selves. Insofar as heteronormative gender dimorphism affects gendered practices of cognition, expression, emotions, as well as sex, sexuality, desire, and fertility, anatomo-politics joins with the disciplinary practices of biopower.<sup>11</sup>

Political biomedicalization (which is central to the intersection of anatopolitics and biopower) assumes a position of dominance as the guarantor and regulator of the gender social health of the population and of the objectified gendered individual.<sup>12</sup> Crucial to that process of domination is

the identification, elimination, or social rehabilitation of individuals with personally and societally dangerous forms of gender psychopathology. Often labeled with other forms of pathology, demonstrating antisocial and criminal tendencies, gender subversive subjects *must* be labeled as suffering from a mental disorder in order to justify the policing practices of hierarchically organized surveillance and the specific forms of disciplinary power that are used.

*INSTRUCTION: Press the POLICE Key*



There is fear in the secular Lands of Gender Dimorphism. Fear of the deviantly gendered Other. Fear of the unhappily gendered Other. Fear of the dangerous gendered Other. To negate their fear, normally gendered people replace it with anger, disgust, loathing, panic, hatred, and abhorrence (Zita 1998, 35). At a societal level, the gendered Other becomes pathologized, demonized, criminalized, and made the “legitimate” personal and institutionalized target of objectification, silencing, scorn, shame, incarceration, elimination, marginalization, and social control. Gender police are crucial to this dynamic.

Gender policing, which must be ubiquitous, works through every dimension of the gender apparatus—from control of the content and access to the dominant episteme of gender disorders, to the introduction of mechanisms that involve the incarceration of, and surgical and hormonal “therapies” performed on the bodies of, individuals classified as “gender disabled.” Gender policing also demands deeply invasive (but self-constituting) self-policing. Thus, we might modify remarks that Foucault makes in *The Birth of the Clinic* (1973) in this way:

The locus in which knowledge [gender normalcy] is formed is no longer the pathological garden where God distributed the species, but a generalized medical [gender normative] consciousness, diffused in space and time, open and mobile, *linked to each individual existence*, as well as to the collective life of the nation, ever alert to the endless domain in which illness [gender dysphoria] betrays, in its various aspects, its great, solid form. (Foucault 1973, 31) [parenthetical inserts added]

Official psychiatric gender experts, many in white-jacketed uniforms, constitute a powerful official police force. Located as the final authorities on all potentially harmful psychopathologies, psychiatric gender experts serve

as the expert civilian police force, often exercising their more public power in juridical settings. Foucault argues that, in secular societies, psychiatrists are charged with guaranteeing the maintenance of the norms of public hygiene and the prevention of social dangers through their identification of “dangerous individuals” (1988, 134). In the context of heteronormative dimorphic cultures, gender dysphorics count as dangerous individuals.

Important as psychiatrists are to gender policing, they are not sufficient for the task. It is clear that ever-vigilant, omnipresent civilian gender policing of the individual and the community, designed to enforce the gender technologies of power and the gender technologies of the self, is necessary in addition to the psychiatric police squad. Hence, the gender police work that psychiatrists perform is complemented by the police work of prenatal diagnosticians, fetal surgeons, obstetricians, pediatricians, family physicians, psychologists, social workers, local religious leaders, teachers, counselors, day care and nursery school teachers.

Foucault notes that it is vital to see how the teachers of young children and parents have become “disciplined” as responsible police. In the area of gender policing, teachers, parents, relatives, and siblings are ideally situated to identify disabling, potentially dangerous, forms of gender identification and sex/gender expression in the young, and to draw these children to the attention of more publicly recognized, institutionally powerful experts in gender surveillance and policing (Foucault 1975, 215). Proof of the success of gender-disciplining children is underscored by the fact that it is other children’s teasing, taunts, and testimony that are used, clinically, as proof of gender dysphoria in children (Feder 1997; Kessler 1998). In present-day North American cultures, the teasing children who ostracize their allegedly gender dysphoric peers constitute the policing tribunal that carries the most epistemic weight for identifying gender-disabled young children. As the good, internationally respected psychiatrist Dr. Zucker puts it,

At least two goals—elimination of peer ostracism in childhood and prevention of transsexualism in adulthood—are so obviously clinically valid and consistent with the medical ethics of our time *that either, by itself, would constitute sufficient justification for therapeutic intervention.* (Quoted in Minter 1999, 18; emphasis added)

Internal safety in gender dimorphic lands is dependent upon a secure gender border. Policing and defending the border are of paramount importance.

*INSTRUCTION: Press the BORDER Key*

In general, border crossers, challengers, and violators do not fare well in societies whose dominant apparatuses depend upon nonpermeable binaries. Often, the threats that these people pose to the binaries can lead to greater protection and intensification of the significance of the border. Regulations and rituals of containment can result in powerfully coercive practices that are used to contain the anxiety and revulsion that the dissolution or violation of boundaries generates (Cromwell 1998). Shildrick (1997, 2002) demonstrates that in cultures that privilege the alleged self-containment of bodies that are classified as “male,” the leakages associated with bodies that are classified as “female” mark “female-embodied” subjects as intrinsically defective, and as symbolic of the dangerous leakage of categories. In similar respects, bodies that are identified as (for example) “defective,” “deformed,” “disabled,” or “grotesque” have variously been contained, segregated, objectified, or annihilated in order to mark and strengthen the border between the nondisabled body and its disabled Other (Shildrick 2002; Thomson 1996, 1997, 2002b). As Erevelles notes, the very viability of the disabled body often involves border crossing into a materialist cyborgian hybridized body whose kinship with, and dependence upon, machines expresses multiple devalued forms of ontological hybridity (Erevelles 2001, 97; Haraway 1991, 1997). Ruthless juridical and social control of racialized and other ideologically naturalized forms of border crossing is more often the rule than the exception (McClintock 1995).

Subjects are disciplined; subjects resist. Ever vigilant for the gender police, gender subversives often target the gender border. Some gender subversives deliberately ignore the gender border; some dismantle it; some appropriate it for transgressive purposes (Devor 1989; Ekins and King 1998). I shall now explicate the distributions of power that are involved in gender subversive politics by returning to the Foucauldian gender apparatus and identifying various reversibilities of power relations that can operate in at least three general modes: (1) challenging the episteme; (2) challenging dominant institutional mechanisms; and (3) privileging subjugated knowledges.

*INSTRUCTION: Press the TRANSGENDER POLITICS Key**MODE 1: Challenging the Naturalist Dimorphic Episteme*

*Carnal Polyvocality* Consider the following self-descriptions (selected from more than one hundred self-descriptions that were sent to Kate Bornstein from all over the world).

I think . . . I am a female fag, who is a drag Queen, who is a mother, has a soon-to-be transman lover and may very well be a tranny himself.

FTM transgendered bulldagger, gentleman stone butch dyke with fag tendencies. . . . Or as my girlfriend says, a drag queen trapped in a woman's body.

I'm a butchy-femme, omnisexual, polyamorous, gender bent, kinky, queer—I am most attracted to queer, genderfuck boys: transboys, boychicks, bioboys.

A bigendered, bisexual switch, a gay/bi FTM drag queen (transfag-drag).

A Lesbian trapped in a man's body. (Bornstein 1998, 8–9)

These carnal living self-descriptions are unintelligible in the modernist gender dimorphic episteme.<sup>13</sup> For these self-descriptions to be intelligible (and livable), a different episteme (and world) must be in existence, an episteme that rejects any form of reductionistic biogenital centrism that collapses gender into genito-sex or that construes sex as simply a given. Linguistic resistance to the dimorphic episteme can be produced in various modes—oxymoronic strategies, parodic strategies, and linguistic anarchy—in order to destabilize its dominance.

*Revealing the Emperor's Tattered Clothes* One form of challenge to the naturalist dimorphic episteme involves revealing the emperor's tattered clothes of the *DSM-IV*, a challenge that can use a variety of means (American Psychiatric Association 1994; Caplan 1995; Prendergast 2001), one of which is the exposure of the backroom politics and shoddy research that often influence the invention of new diagnostic categories. Another means involves revealing the duplicity at work when adult homosexuality appears to be *de*-pathologized (i.e., is removed from the *DSM*) only to be *re*-pathologized with its (re)introduction as one of the “reliable indicators” of pathological gender dysphoria prevalence rates in children and adolescents.<sup>14</sup> So clear is this association in heteronormative gender-dimorphic cultures, that many distraught homophobic and transphobic parents take their “feminine sons” to the psychiatric gender police to ward off adult homosexuality and transsexuality.

*Designing Destabilizing Forms of Gender Psychopathology* This mode of challenge appropriates diagnostic mechanisms of the *DSM-IV* in order



to pathologize dimorphic individuals who (currently at least) are normalized within the terms of the dominant gender episteme. For example, one might propose that the following definition of a mental illness be included in the *DSM-V*.

*Dimorphic Gender Euphoric Disorder (DGED)*: A form of mania which results from gender dimorphic rigidity and obsessive judgmental tendencies to polarize all persons, behaviors, and social practices involving sex, sexual desire, gender, and fertility.

*Co-morbidities*

- Disturbing forms of permanent dimorphic demands for breast implants, muscle implants, penile elongations
- Self-defeating behaviors such as make-up-identity dependence and hair-induced forms of agoraphobia
- Addiction to cosmetic psychopharmaceuticals
- Intense, uncontrollable transphobia

*Normalizing Dimorph-Phobia* This challenge involves the replacement of irrational homophobia and transphobia with dimorph-phobia, which then becomes the only reasonable source of fear. At present, the dominant dimorphic Gender Apparatus, with its extended heterocentric history of systemic oppression and gender dimorphic disciplining practices, normalizes the annihilation, silencing, humiliation, harassment, persecution, or ‘curing rehabilitation’ of anyone not dimorphically defined. *It is reasonable to fear this Apparatus*. A clear corollary to fear of this heterocentric project involves (as it were) “returning the policing gaze” that is at the center of oppressive dimorphic surveillance practices.<sup>15</sup>

*Appropriating Social Constructionist Paradigm Reversals* This form of challenge to the gender dimorphic episteme involves the appropriation of social constructionist strategies and paradigm shifts that have proven effective in psychiatric survivor movements and disability rights movements (see Beresford, Gifford, and Harrison 1996; Beresford and Wallcraft 1997; Corker and Shakespeare 2002). In her pivotal collection *Current Concepts in Transgender Identity* (1998), Dallas Denny points out that the biomedical psychopathologizing of people who identify as transsexual has rendered invisible the fact that those children, teenagers, and adults are likely to lead lives that are filled with alienation, abuse, terror, and discrimination. When those *political* facts are taken into account, Denny says,

The important questions then become not “Do transsexuals exhibit significantly more psychopathology than nontranssexuals?” but “What environment stresses do transsexuals encounter, how does this affect them, and how can we ensure that they are treated better?” *The locus of the problem changes: it is externalized*. . . . It is not the transsexual or transsexualism that is at fault; the problem is an intolerant and violent society. (1998, 425; emphasis added)

In short, this form of challenge shifts the locus of pathologizing behavior, locating it at the center of the “normal” and normalizing culture (Davis 1995; Morgan 1991, 2002).

*Appropriating the Discourses of Power* The International Bill of Gender Rights, which was adopted on June 17, 1995, by the International Conference on Transgender Law and Employment Policy, challenges the nature of the link that is made between the episteme and governmentality of the Gender Apparatus (Feinberg 1996). The bill is grounded in a discourse of individual rights, freedom of sexual and gender expression, adoptive and custodial rights, and freedom from psychiatric diagnosis or treatment solely on the basis of gender identity or expression. Because the bill employs the language of universal rights and disavows any limitation to special interest groups, it generates a counterdiscourse that undermines a structuring of rights as either normal or pathological (Feinberg 1996, appendix A, 171–75).

### *MODE 2: Challenging Dominant Institutional Mechanisms*

*Law* It is no accident that the International Bill of Gender Rights was adopted by a group concerned with transgender law and enforcement policy. Gender discrimination in employment and forms of judicial discrimination against transgendered people are rampant. Furthermore, critics have pointed to the oppressive legal and social consequences of documentary visibility, that is, gender identification on passports, driver’s licenses, and so on. Transgender scholars, activists, and their allies who are fighting for radical judicial change of the current dimorphic state of affairs work with discourses of global transgender rights, transgender jurisprudence, and transgender justice (Findlay et al. 1996; Grenfell 2001; Petchesky 2001; Rothblatt 1995; Sharpe 2002).

*Universities* The appropriation of dominant mechanisms of the academy is crucial to denormalizing heterocentric dimorphic theorizing, research,

pedagogy, and practice. The appointment of sexual diversity equity officers and queer scholars, the establishment of programs in sexual diversity studies, transgender studies, and queer studies, access to prestigious research presses, and the occurrence of international transgender congresses, where transgender scholarly, political, and phenomenological-experiential knowledges are legitimated, work in combination to destabilize dimorphic mechanisms (Tremain 2000, 2002).

*The Psychiatric Establishment* In the mid-1990s, Phyllis Burke, a lesbian mother, put the custody of her son at risk in order to publish *Gender Shock: Exploding the Myths of Male and Female* (1996). Burke had burrowed through stacks and stacks of the medical histories of young children who were deemed “gender inappropriate” in order to expose the appalling dimorphing micropolitics and disciplining that had been directed at the children, their siblings, and their families. On the basis of her research, Burke courageously identified the ways in which the American Psychiatric Association, in conjunction with the well-funded university-based Gender Identity clinics, constructed some genders as disabling mental illnesses. In so doing, Burke exposed to public view the oppressive inner maneuverings of the Apparatus of Gender.

*Schools* In some public school systems, educators have established “Rainbow Schools” for children and teenagers who do not wish to be gender dimorphed in the Pinking-and-Blueing public schools (Britzman 1995; Bryson and deCastell 1997; Feinberg 1998; Sedgwick 1990b). While strategies like these run a major risk of serving as sex/gender ghettos, publicly (and dangerously) marginalizing students now “diagnosed” with “special needs,” they also promote an educational paradigm that calls into question the totalizing educational completeness of gender dimorphic education. As Rainbow schools, Rainbow day-cares, and Rainbow nurseries increase in numbers, and as the children and teenagers who attend them learn about and experience more inclusive curricula, personal respect, community sustainability, and ideals of social justice, Pinking-and-Blueing schools will be decentered as the only normal schools. Indeed, they may eventually come to be regarded as potentially dangerous, since the students who attend them would probably be more likely to suffer from dimorphic gender euphoric disorder (DGED).

*Modes of Cultural Production* Incorporating public narratives and public iconographies of “transgender warriors who fell in battle” (Feinberg

1996) into queer and transgender cultures of poetry, music, videos, photography, and cyberspace are crucial to rendering transgender visible—and safe. Publishing “dangerous” books that deconstruct the apparent naturalness of the dimorphic mechanisms is also important. One of these dangerous books is Kate Bornstein’s *My Gender Workbook* (1998), which is deliberately printed in the recognizable format of a school workbook. Witty, subtle, accessible, interactionist, personal, profound and political, Bornstein’s book queers virtually every dimension of gendered dimorphic existence in North America. Leslie Feinberg’s *TransGender Warriors: Making History from Joan of Arc to Dennis Rodman* (1996) is another “dangerous” book. In the introduction (which exemplifies Foucauldian genealogy at its best), Feinberg writes:

It is time for us to write as experts on our own histories. . . . My goal in this book is to fashion history, politics, and theory into a steely weapon with which to defend a very oppressed segment of the population . . . [I]f theory is not the crystallized resin of experience, it ceases to be a guide to action. I offer history, politics, and theory that live and breathe because they are rooted in the experience of real people who fought flesh-and-blood battles for freedom. (1996, xii–xiii)

When Feinberg fashions sex/gender inclusive and racialized history, politics, and theory “into a steely weapon,” the weapon that is devised glints off of the steely weapons that have been forged within the powerful gender apparatus. The weapons of the gender apparatus have included knives, needles, microscopes, computers, guns, fists, penises, hangmen’s nooses, steel corsets, censorship, diagnostic manuals, and white lab coats. By claiming a history, a politics, and a theory, Feinberg appropriates the dominant mechanisms of many apparatuses in order to create a counterapparatus in which the racialized silence, distortion, and oppression of gender variation is no longer possible.<sup>16</sup>

### *MODE 3: Privileging Subjugated Knowledges*

The resisting subjects of subjugated knowledges and buried knowledges of erudition, whom dominant epistemes and privileged epistemic subjects negatively define, are central to any political drama (Foucault 1980b, 82). Because the subjugated knowledges of transgender are grounded in a kind of gender-*cogito* of phenomenological certainty that is lived under circumstances of almost inconceivable material oppression, violence, and personal

sacrifice, they usually remain just that: *subjugated* knowledges. While these knowledges often involve a radical decoupling from genito-biocentrism of any sort, they remain, understandably, publicly hidden. Many subjects who are subjugated by the dominant Gender Apparatus choose to pass, to survive, rather than to “fall in battle.” Gender police are everywhere—in our families, in our workplaces, in our communities of origin, in our bedrooms, in our neighborhoods, in our children, in our communities of faith, and in our souls. In coming out, all might be lost. It is important, therefore, to recognize the risk and the courage of gender-subjugated subjects who make themselves evident within the matrix of the current Gender Apparatus (Califa 1997; Courvant 2000; Feinberg 1998; Holmes 1997–98; Sedgwick 1990a).

Insider-survivor narratives are vital means with which to contest the dominant episteme.<sup>17</sup> Insofar as a range of gender identities and expressions are codified and politically controlled as psychopathological gender disabilities, “insider” subjugated knowledges can (and do) play a necessary galvanizing political role. Narratives such as Daphne Scholinski’s *The Last Time I Wore a Dress: A Memoir*, Ladelle McWhorter’s *Bodies and Pleasures: Foucault and the Politics of Sexual Normalization*, and Leslie Feinberg’s *Stone Butch Blues* demonstrate how their authors survived “therapeutic gender incarceration,” appropriated medical records, and used experiential knowledge to challenge the hegemony of gender dimorphism. This is still a dangerous process. For voicing one’s subjugated knowledge and acknowledging one’s location *as* a location of oppressed subjugation can also serve to *intensify* one’s subjugation in relation to the dominant Gender Apparatus (Hausman 1995).<sup>18</sup>

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→ ←

While each of the three modes that is described above challenges the dominant Gender Apparatus in necessary ways, even in combination they are not sufficient to subvert it. Given the public nature of these modes, furthermore, they can make gender policing simpler and more dangerous, with the result that the temptations of “respectable dimorphic assimilation” become all the more irresistible. In light of the protean heterogeneity of the Gender Apparatus, therefore, a more hybridized coalition politics of resistance is needed.

The gender apparatus does not operate in isolation; on the contrary, it is imbricated in (for example) powerful transnational Race Apparatuses that operate in oppressive, materializing ways. In the nineteenth century,

the sex/gender border was, as McClintock points out, seen to be dangerously permeable in terms of certain class and racialized crossings. As a consequence, colonizing Gender Fertility Police sought to regulate access differentially to women's sexuality, especially the sexuality of privileged white women in order to sustain "white control of progeny, property, and power" (McClintock 1995, 47). In the twentieth and twenty-first centuries, the sex/gender border is implicated in systemic ways with the Apparatuses of neocolonial global imperialism, geneticized and eugenicized ableism, transnational technoscience, quasi-essentialist and fundamentalist epistemes of culture and ethnicity, and naturalizing theories that justify violent patriarchy.

The police often "moonlight" for many Apparatuses, as they patrol, serve, and protect the social order. And when they sleep, we police ourselves . . .

#### NOTES

1. I arrived at this conclusion, in 1979, after a comprehensive analysis of theoretical and empirical arguments that were at the time advanced to demonstrate the necessity of sex/gender dimorphism (Morgan 1979). Since that time, the empirical and speculative terrain has shifted with the rise of (for example) discourses of evolutionary psychobiologists; in addition, theoretical understandings of sexuality have become more ontologically nuanced as a result of virtual and cyborgian modalities of human erotic embodiment (see Haraway 1991; Stone 1991). I would, nevertheless, advance the same claim today (see Kessler and McKenna 2003; also see Shapiro 1991; Spanier 1991). It is for this reason that undertones of horror permeate the first section of this chapter.

2. Naomi Scheman (1999) articulates this notion of "perinatally pink-ing and blue-ing" in an extraordinarily original paper entitled "Queering the Center by Centering the Queer: Reflections on Transsexuals and Secular Jews."

3. Ladelle McWhorter (1999) introduces the notion of "honorary heterosexual." I extend McWhorter's notion to "honorary dimorphians": individuals in Gender DiMorph Utopia who situate themselves in a way that performs "border respect." In this context, some lesbians, gay men, bisexuals, and transsexuals could be seen as "honorary dimorphians" as long as they contribute to the preservation of the dimorphic border through constancy of their dimorphic identity affiliations and sex/gender practices. See also Halberstam 1998.

4. I privilege the notion of "Gender Border" in this dys-utopia in order to emphasize what I see as the extraordinarily powerful role that form, boundary, limit, and constancy have played in the Western theoretical and political imaginary from the pre-Socratic philosophers to present-day racialized military conflicts. "Protecting borders" is a full-time preoccupation, not only for political strategists and gender dimor-

phians, but also for immunologists and ethno-racial purists. My discussion in this chapter builds upon recent postmodern and postcolonial theorizations of border, diasporas, margins, liminality, transgressions, and unpredictable (hence, dangerous) displays of formlessness. See, for example, Braidotti 1994; Douglas 1966; Kristeva 1982; McClintock 1995; Shildrick 2002.

5. The extent to which recent advances in prenatal fetal surgery are employed to “correct” sex/gender “anomalies” should not be minimized. See Casper 1995; Dreger 1998; Morgan 2002. For the most recent work on surgical interventions in response to postnatal intersexuality, see Kessler 1998; Fausto-Sterling 2000; Holmes 2000, 2002, 2005. For an example of the foundationalism of current biomedical thinking, see “Etiology of Gender Dysphoria” in Ettner 1999. The author of that paper approvingly cites White’s theory with respect to the interaction of active neuronal pruning and neuronal migration with prenatal “sex” hormones in the third trimester of pregnancy as “*the* process responsible for normal gender identity development” (55; emphasis added). Empirical results are linked to data collected from cranial autopsies of “sexually anomalous” individuals. In GDU, this sort of research would receive extensive public support.

6. This is in fact a “real life” example that Robert Crouch reports and documents (1999, 46).

7. The details of the story of Susan are drawn directly from a fully documented—and congratulatory—case study reported by Baumbach and Turner (1992). The stories of Daphne, Leslie, and Ladelle refer, respectively, to the life experiences of Daphne Scholinski (1997), Leslie Feinberg (1993), and Ladelle McWhorter (1999). See Bockting and Coleman 1992 for a terrifyingly “comprehensive” model of “treatment.”

8. Lest the reader think that this sort of diagnostic surveillance seems far-fetched, recall the continuing influence of Reker’s diagnostic behaviorism in contemporary psychiatric gender identity theory and practice. Reker created a definitive list of gender-normative gestures as a privileged test to identify gender mental disturbances in children and adolescents. The extent to which these gestures continue to be publicly recognizable in homophobic sites of cultural production in North America and appropriated in various forms of queer camp is evidence of normative gender dimorphism at work. See Burke 1996 for a discussion of Reker’s work and influence.

9. I disagree with scholars such as Bryan S. Turner who argue that Foucault is primarily preoccupied with carceral societies, that is, societies that “involves a regime of micro-regulations and disciplines which operate through a complex web of self-subjection” (1997, xvii). My own view is that Foucault’s notions of apparatus, bio-power, and governmentality are sufficiently subtle and complex to analyze risk societies in addition to carceral societies. I would argue that *gender* offers an interface between the material and discursive realms that illuminates how carceral and risk societal dynamics dialectically engage. Contemporary disability studies that concern the nature of “the disabled subject” also demonstrate why carceral and risk societies should not be treated as mutually exclusive. See Erevelles 2001; Ghai 2002; Price and Shildrick 1998; Shildrick 2002; Thomson 1996, 2002a, 2002b; Tremain 2001.

10. Included on the list of “subversives” in GDU are Kate Bornstein, Rosi Braid-

otti, Judith Butler, Pat Califia, Cheryl Chase, Jason Cromwell, Dallas Denny, Holly (now Aaron) Devor, Richard Ekins, Anne Fausto-Sterling, Leslie Feinberg, Marjorie Garber, Elizabeth Grosz, Bernice Hausman, Suzanne Kessler, Wendy McKenna, Ladelle McWhorter, Nelly Oudshoorn, Daphne Scholinski, Sandy Stone, Shelley Tremain, and Jacqueline Zita.

11. See Price and Shildrick 1998 for a detailed analysis of the micropolitics of this process.

12. For historical accounts see, for example, Oudshoorn 1994 and Van Den Wijngaard 1997. For an extended and brilliant analysis of contemporary techno-biomedical politics, see Clarke et al. 2003. See also Morgan 1991, 1996, 1998a, 1998b, 2002 for specific medicalization and theoretical analyses.

13. A cautionary note here: attempts to engage in *strategic reversibility* of the dominant gender dimorphic dominant apparatus and its category of gender disability can result in the reappropriation by the dominant apparatus and carnal *reinscription* of the very gender dimorphism that these strategies aim to subvert. The dominant gender apparatus is both supple and resilient. For a classical discussion of this dynamic, see Butler 1990. See Thomson 2000a, 2000b for analyses of this dynamic in cultural iconographies of disability.

14. Although the authors of the *DSM IV*, gender identity researchers such as Bradley, Green, and Zucker, and some clinical practitioners acknowledge that not all gender dysphoric children and adolescents become homosexual adults (some become transsexuals and others become nontranssexual heterosexuals), the inference of “prevalence” that these authors and researchers make assumes that it is a necessary (though not sufficient) condition of adult homosexuality that one suffered from some form of gender disability (i.e., gender dysphoria or a gender identity disorder) in childhood or adolescence. See Corbett 1999; Feder 1997; Minter 1999; and Pleak 1999 for analyses of these claims.

15. In order to understand how transgressive political movements critique the ways in which dominant gazes and (technoscientific) practices of surveillance, one must explore the political-ocular phenomenology of “the oppositional gaze” and dominant gazes. This dynamic is critically explored in the context of antiracist politics by Bannerji (1993), hooks (1992), and Razack (1998); in disability politics by various authors in Fries 1997, authors in Thomson 1996, Thomson 2002b, contributors to Tremain 1996b, and other disability scholars; in queer politics by Altman (2001) and others. The classical sources for Foucault’s theoretical claims about “the gaze” are *The Birth of the Clinic* (1973) and *Discipline and Punish* (1975).

16. Feinberg’s explicit attention to racialized transgender history is to some extent an exception to much of American transgender scholarship. On the lack of theorizing racialized queer subjectivities, see Hammonds 1997. For an illuminating examination of racializing contexts, see Zita 1998.

17. I use the term *narrative* to mean a deliberate rhetorical construct, not to intend an “innocent mirror of experience.” Narrative accounts, which have served a galvanizing political role in diverse political liberatory movements, are especially critical in contexts (such as the contexts of psychiatric survivor politics and disability rights politics) in which the very capacity to originate a narrative is in question. See, for



instance, Beresford, Gifford, and Harrison 1996; Beresford and Wallcraft 1997; Tremain 1996a.

18. In 1994, the transgender psychologist, writer, and activist Dallas Denny did not feel safe coming out as a transsexual. In 1998, Denny wrote: “I am a woman of transsexual experience . . . I am happy and proud to claim my status as a living expert” (1998, xvii). While still at risk in a genderist society, Denny is protected and privileged in multiple ways: by credentials, professional experience and allies, by a visible community, by the publication of the International Bill of Gender Rights (Feinberg 1996), by the rise of transgender law (Findlay et al. 1996; Grenfell 2001; Currah 2002; Sharpe 2002), and by the rise of global Sex/Gender rights movements. Not everyone’s subjugated knowledge will, however, be as respected as is Denny’s. In speaking about the complex politics of invisible disability and the loss of individuality that can result when one publicly identifies “as disabled,” the lesbian poet and essayist Ellen Samuels highlights the critical role that privilege can play in relation to subjugated knowledges. As Samuels bluntly puts it, “I think it is difficult to argue that today’s society would be at all transformed by learning that homeless people, women on welfare, people with disabilities, or any other socially disadvantaged group had also come out of the closet as gay” (1999, 200).

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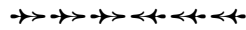


*Disability and Governmentality in the Present*





DANIELLE PEERS



## From Inhalation to Inspiration

### *A Genealogical Auto-ethnography of a Supercrip*

*The cold, fume-filled air burns my lungs with crackling asthmatic fire, as I wheel down a busy winter street, the flickering Olympic torch in hand. A warm swell of pride expands my chest as strangers loudly cheer me on: “Good for you!” “Isn’t that amazing?” “What an inspiration!” I grin, widely. I want to inspire people; I want to prove to them how able disabled people can be. The rush of pride quickly turns to chest-squeezing, breath-stealing panic as I jolt to a stop. My front casters catch and burrow deep into uncleared snow. My slick Olympic-issue mittens slide uselessly across wet push-rims. I am stuck, in more ways than one. No matter what I choose—to stay stuck, to stand up out of my chair, or to get someone to push me—my inspirational status will be undermined, along with my vanity and my benevolent activist intentions. I will become either the evil faker or the pitiful, unable dependent: just another revolting gimp.*

Hyper-able disabled public figures are often celebrated as both inspirational role models and important advocates for their disability communities simply because they spread, in virtue of their hyper-ability, so-called positive images of disability (Hardin and Hardin 2004; Kama 2004). In direct response to this popular inspirational reading of hyper-able disabled figures, disability scholars like Marie and Brent Hardin argue that the inspirational “supercrip” narrative “serves as a hegemonic device that keeps people with disabilities at the bottom of the social hierarchy and deflects the culture’s responsibility for its ableist infrastructure” (2004, 1.3). In other words, supercrip narratives—inspirational stories about hyper-able disabled people, that is—reproduce the expectation that disabled people should each individually overcome their tragic and inferior embodiment in

order to become productive members of normative society. In this way, supercrip stories reinforce the idea that disability is a problem intrinsic to disabled people themselves, rather than intrinsic to the matrix of problems that arise due to disabling architecture, policies, attitudes, and a host of other factors. Furthermore, because supercrip stories celebrate hyper-able disabled people who overcome their bodies in order to accomplish major feats, these stories also tend to create unrealistically high expectations of what *all* disabled people should be able to accomplish. These high expectations serve to justify the vilification of particular disabled people who do not manage to overcome, often by writing them off as stubborn or lazy and therefore deserving of the poverty or lack of care that they may experience (Clare 1999; Kama 2004). In what follows, I use the term *revolting gimp* in order to refer to this disabled figure who either cannot or will not inspirationally overcome disabling circumstances. The term *revolting*, in particular, is intended to convey a double meaning: to convey the intensity of social devaluation that disabled people who do not overcome disability face and to convey that there can be a certain revolutionary potential that (as I will argue later in this chapter) might accompany a refusal of inspirational supercrip status.

*Disciplining the Supercrip Body:  
the Ins and Outs of Inspiration*



*The heavy, sweat-filled air drowns my tired lungs as my aching, swollen, ten-year-old legs carry me back and forth between basketball sidelines. My coach sits up in the bleachers where he observes us, keeping a keen eye on his stopwatch. I struggle to keep my face relaxed, my breath efficient, trying not to let my coach see me grimace in pain. Real athletes don't let pain stop them. I cling to my coach's oft-repeated breathing mantra, which now loops relentlessly in my head: in through mouth to belly—step, step—out through mouth, relaxed—step, step. His voice weaves my breath and steps together, a cadence growing as familiar and natural to me, as, well, as my own breath.*

What could be more intimate, mundane, or natural than one's breath: the seemingly instinctual rhythm of inspiration and expiration? According to Foucault (1995), it is precisely this understanding of human capacities, that they have natural instinctual courses of development, that renders them

targets of disciplinary power. Discipline is intended to shape, normalize, and influence the “natural” capacities of each human into more efficient, useful, or governable forms in ways that propel humans to “draw on their own inherent energy and power to do so” (McWhorter 1999, 155). My coaches, for example, did not give me breath. They did, however, subject me to repetitive disciplinary practices that shaped my breath into increasingly athletically useful and efficient forms. They helped to mold me into the *kind* of person who would continuously monitor, discipline, and use breathing toward increasingly athletic ends. The training regimes that my coaches imposed on my teammates and me seem, in retrospect, to have been lifted straight from the pages of Foucault’s *Discipline and Punish* (1995). Coaches would, for example, strategically dissect spaces and calibrate increments of time in order to specify the rate and effort of our breath and strides in ways that would ultimately better enable them to monitor, rank, and punish us in relation to our shifting athletic capacities. They would observe us from the bleachers and inspect our performances through videos, rendering us constantly visible, inciting us to continuously monitor ourselves. They implemented drills that meticulously worked on coordinating my most minute, and most intimate, gestures with particular temporal rhythms, with other bodily gestures, and with the sporting objects with which I engaged. Beanbags on my belly induced me to breathe first with my diaphragm, then to expand my breathing into my ribs. A metronome, and later an internalized repetitive mantra designed to create more regular and efficient breathing, pulled the cadence of my breath to the perfectly calibrated length of my stride. Repetition under scrutiny built a seemingly instinctual exhalation into the moment before a leather ball left my hands in a foul shot. Meditation practice taught me to use specific patterns of breathing to push past pain and exhaustion. In combination, these daily practices increasingly molded my breath, body, and identity into the breath, body, and identity of an athlete.

*The footsteps have faded out, but the rhythm of sweat-filled breath, woven together with movement, remains: in through mouth to belly, pull shoulders back, out through mouth controlled, push down hard on wheels. Up on the wheelchair treadmill, I push the looping rhythm of my breath-movement progressively faster. I push toward the point of puking into the thousand-dollar windpipe that measures the cadence, depth, and gaseous efficiency of every breath I take. I no longer need a coach to push me. I have internalized the demands and disciplinary practices of all the coaches who came before.*

*The rhythmic breathing returns, out on the street after practice, as I wheel up a steep hill to my car. I struggle to keep my face relaxed, breath efficient. I try not to let the passersby see me grimace with the pain of a recently sprained shoulder. Real athletes don't let pain stop them. Someone offers to help by pushing me up the hill. I snap: "I don't need any help, I'm a Paralympian!" I turn my focus inward again, quieting my breath so that the grueling push appears effortless. I weave this breath into even longer, more powerful strokes. I want to look so athletic that no one would ever imagine that I would need someone to push me. I have internalized the demands and disciplinary practices of the inspirational, hyper-able supercrips who came before me.*

By the time I began to train for the Paralympics, I had internalized the disciplinary lessons taught to me by the many coaches of my “able-bodied” past. This previous training rendered me fully capable of shaping my own capacities through carefully calibrated dissections of time and space, through perpetual self-testing and the meticulous coordination of each breath with the rhythm of a push and the trajectory of a wheel. Such coaching had made me more than able to discipline myself, and more than willing to do so. This compliance to self-discipline did not, however, minimize the surveillance to which I was subjected. In fact, the surveillance of my capacity to self-discipline became increasingly dispersed and ever present. I became the subject of and subjected to long-distance digital surveillance afforded to trainers through data from windpipes and heart-rate monitors, intermittent in-person surveillance of coaches watching from up in the bleachers at training camp, perpetual surveillance by every passerby on the street, and, perhaps most important, constant self-surveillance. Each judging gaze pushed me to demonstrate my increasing capacity to discipline myself.

The web of surveillance to which I subjected myself shifted markedly when I started using tools of mobility outside of sport. Teammates, friends, and strangers constantly reminded me that in order to be recognized as a disabled athlete I needed to develop the capacity to inspire like an athlete, in both senses of the word: to breathe in (with athletic strength) and to have a heroic effect (and affect) on others. Like my capacity to breathe, these other heroic, inspirational capacities were developed in me through the constant surveillance and shaping of a whole series of additional capacities, including independent mobility, athletic negotiation of inaccessible structures, and the capacity to narrate and enact disability in culturally legible ways. Because I had come to internalize the need to be a site of inspiration,

I also came to internalize the sense that the cadence of my wheeling, the uprightness of my posture, the effortlessness of my breath, and the strength of my voice were constantly under surveillance by the people around me, as well as under threat of suspicion by them. I meticulously trained myself out of every possible sign of “gimpy” fatigue or pain that would call into question the legitimacy of my supercrip status. I simultaneously trained myself out of leg movements and other signs of ability that would call into question the legitimacy of my disabled status. Strangers, too, actively policed my inspirational disabled status insofar as their inspired looks often changed to looks of disapproval—which were sometimes even accompanied by angry accusations that I was a “faker”—if and when I moved my legs, stood up from my wheelchair, or switched from my wheelchair to my crutches, and vice versa. I came to learn that the capacity to inspire is linked to the capacity to act *as if* I were a stereotypical disabled subject with a complete spinal cord injury. I was obligated to act *as if* I were the disabled person that strangers had expected *before* I would be celebrated for the ways in which they perceived me as having heroically overcome my disability. My teammates also shaped my inspirational capacities. They taught me—largely through their ridicule of other disabled people—how to co-ordinate my newly developed inspirational movements with the tools that I use. For example, they taught me to strip my wheelchair of any superfluous comforts: no high backrests or armrests to detract from my disciplined posture; no push handles to distract from my fiercely cultivated independence; no seat belts, anti-tip bars, breaks, or gloves to make me look “gimpy.” By watching my most inspirational friends and teammates, furthermore, I learned to perform athletic maneuvers on the street such as appearing “relaxed” while balancing on my two rear wheels and climbing stairs while seated in my chair. With this instruction, my most inspirational friends and teammates convinced me that if I mastered these dangerous (and often functionally superfluous) moves, people would take my inspirational athleticism seriously.

Both my coach-led training to become increasingly self-disciplined and my peer-led disciplinary training to become increasingly inspirational significantly increased various capacities, the outcomes of which were some remarkable and uncommon life opportunities such as sponsorships, public-speaking opportunities, and national media exposure. Nevertheless, this disciplinary process of inspirationalization also had its costs. As Ladelle McWhorter explains it, “[N]ormalizing disciplinary practices may tremendously enhance a person’s ability to perform certain kinds of functions or accomplish certain kinds of tasks, but they decrease the number of different

ways a person might be able to respond in a given situation; they narrow behavioral options” (1999, 137). In other words, discipline not only increases certain capacities in the disciplined individual, but it also makes that same individual increasingly *docile*, that is, discipline makes people more controllable, more predictable, more open to further discipline, and more eager to discipline themselves (Foucault 1995). Indeed, the more I trained in both forms of inspiration, the better I became at each technique but the harder it was to practice—or even recognize—alternative ways of moving, breathing, and being. The more I trained, the more trainable I became: more and more of my capacities came under the disciplining surveillance and practices of more and more experts, who could more readily shape my actions and capacities according to their needs. The more I trained, the more invested I became in my inspirational athletic identity and the less willing I was to take any action, or tell any story about myself, that would not reproduce this identity. In other words, the more I invested in my hyper-able capacities and identities, the narrower my range of possible actions became. In order to merely be recognized as an athlete and to recognize myself as one, I was willing to restrict my mobility and capacities (for example, by narrowing the range of tools that I used); increase my pain, fatigue, and muscular degeneration (for example, by not using a backrest); and risk serious injury and possible interruption of my athletic career (for example, by learning to balance on two wheels without anti-tippers). In short, my increased capacity for inspiration was accompanied by a certain docility on my part.

*The room is quiet but for the soothing voice of our team psychologist and our synchronized, obedient breath. She prompts us to breathe in deeply and to imagine our breath moving all the way down to our toes, relaxing each muscle in succession as we breathe out. I feel my breath move into my chronically dislocated hip. I flinch and then regain composure, using the familiar inspiratory rhythm to push through pain into relaxation. I can't help but wonder how my teammates are doing. Do they breathe deeply into a painful, absent, unsensing, or prosthetic limb without flinching? An idea emerges. My hands grasp the crutches at my sides and I guide my next breath deep into their rubbery tips. I feel an embodied sensation of my breath tracing their contours and density, aspects of my crutches that I have explored intimately through the repetitive sharing of weight and time. The muscles we have developed together, through our shared movement, twitch with the pleasure of this exploration. These sensations are more real and relaxing to me than the instructed movement of breath through my supposedly natural legs.*

“We believe,” Foucault famously states, “that the body obeys the exclusive laws of physiology, and that it escapes the influence of history, but that too is false. The body is molded by a great many distinct regimes” (2003a, 360). Through his genealogies, Foucault (1995, 2003a) seeks to historicize and politicize the aspects of our bodies that seem most natural and apolitical, including our sensations, our desires, and even the very shape and capacities of our flesh. McWhorter develops this point further, arguing that disciplinary regimes render sensations “subject to diminishment, intensification, and qualitative variation through time and with cultivation or exercise” (1999, 179). That is, disciplinary regimes are often used to actively cultivate pain, suffering, and other physical and psychological sensations because they are useful for producing more disciplined and docile subjects (Heyes 2007).

Within sporting and inspirational disciplinary regimes, my bodily sensations were often strategically utilized, actively produced or shaped in ways that rendered me increasingly open to further discipline. Coaches often coercively used the burning sensation that highly fatiguing exercises produced in me in order to increase my docility, perpetually re-designing the exercises to make them increasingly and differently painful as I developed the capacity to withstand the increased pain that they caused. At the same time, the nausea that ensued when I pushed through the fatigue that repeated, long races in the wheelchair caused came to produce in me a pleasurable-painful sensation. Because of the inspirational self-practices I cultivated, I became ashamed to receive various types of mundane assistance (such as a push up a steep hill). Meditative breathing exercises enabled me to cultivate the (physiologically erroneous) sensation that I was actually breathing deep into my legs or crutches, as well as to develop the capacity for deep relaxation and pain control, both of which capacities helped me to train through injury and stress. In sum, my bodily sensations have very particular local histories and very specific calibrated uses.

My desires, too, have their own histories. Multiple times every day, for eight years, I trained in the skill of tilting up and balancing on one wheel. This history, mixed with four years of medically induced retirement from wheelchair sport, has produced a recurring, compulsive desire—a physical bodily craving—to feel that ratchet-strap pull against my dislocating hip into the momentary weightlessness of a tilt. I imagine that this deep sensation of longing is similar to what nondisabled people erroneously assume that I feel for bipedal ambulation. Is longing to walk any more natural than longing to tilt? Is the chair or the crutch any less a part of my body than my legs are? My body shape, my capacities, my sensations, and my qualities of



movement are molded and extended by the different tools with which I mobilize. The aluminum crutches with which I swing up a flight of stairs, like a six-foot quadruped, extend my straining shoulders and arms. At another moment, however, I glide with the ease of a four-foot-tall titanium wheelchair user who gets stuck at the bottom of the very same flight of stairs. The height, shape, capacities, and movement patterns of my body shift with each “body-object articulation,” that is, they shift with every disciplined relationship I form with a tool of mobility (Foucault, 1995, 152). My tools are articulated with my body at great cost: each high-tech, light-weight tool costs thousands of dollars to buy and requires that I train for thousands of hours in order to learn how to use it proficiently. My tools and my body mold each other through this repetitive training in ways that make it increasingly hard to differentiate body from tool. I can physically feel the precise contours of the smallest pebble that my rubber wheel or crutch tip bends to enfold. My body instinctually adapts with shifted weight, a largely unconscious process no less natural or intuitive than the shifting of weight between one’s feet. My tools have become embodied. Rose Nikolas explains, “Human being is emplaced, enacted through a regime of devices, gazes, techniques which extend beyond the limits of the flesh into spaces and assemblies” (1996, 143). In other words, we come to embody the disciplinary techniques, tools, technologies, and knowledges that we use, and that are used on us. I learned, trained, and paid to move like a hyper-able inspirational athlete, and both this movement and this training became components of my very embodiment and subjectivity. My hyper-able disabled body is made up in equal parts of crutches and dislocated bones, absent backrests, and metronomes.

My bodily sensations, my desires, my various body-object articulations, and the very contours of my flesh are as much an effect of “the iron hand of necessity” as of the “dice-box of chance” (Friedrich Nietzsche, in Foucault 2003a, 361). The workings of power, as well as a series of random events or mistakes, have shaped my body and its capacities. My current embodiment is not an inevitable outcome of stable structures of power. I could easily have ended up otherwise. My broad shoulders, for example, have been precisely molded by the disciplinary weight-training regimes of the personal trainer my coach assigned to me. My atrophied legs, on the other hand, are largely the effect of my doctor’s contraindications for strenuous lower-body workouts. My body shape is thus the contingent effect of medical and sporting relations of power. Both my trainer and my doctor gained access to my body through incredibly random events: a series of unlikely scenarios whereby a stranger invited a seemingly nondisabled version of me to a

wheelchair basketball practice, which led me to meet a sport official who happened to recognize my gait pattern and sent me to a neurologist for testing. Eventually, through a whole series of lucky breaks and strategic navigations of Paralympic power relations, my diagnosis gained me eligibility for the Paralympic team. This history of accidents, reversals, and plays of power is largely absent from the inspirational stories that are told about me. The inspirational supercrip story about me would have you believe that I overcame a naturally disabled body through a naturally endowed sense of self-discipline and willpower. These supercrip stories would have you believe that the inspirational effect of my overcoming is also perfectly natural, perhaps even inevitable. My embodied histories of both power and chance are erased through the inspirationalization of my biography.

### *Subjecting the Supercrip: Inspiration or Expiration*



*Fresh oxygen scorches my lungs for the first time. Having been pushed out of my mother, thanks to her own disciplined Lamaṛe breathing, my first breath is beat into me by the hand of a benevolent doctor. My skin shifts from the blue-white hue of oxygen deprivation to the distinctly red hue of trauma. My loud, ear-splitting wail prompts the doctor's confident assertion, "It's a healthy baby girl! Strong lungs. Ten fingers. Ten toes." With that first sloppy, mucus-filled, independent breath, I begin my voyage as a healthy human being.*

Judith Butler (1988) argues that one of the first constituting acts of subjectivity is the sexing of newborns. The movement from *it* to *girl* in the declaration "It's a girl!" is the first of many sexing technologies that secure an essential part of our subjectivity. Yet, before the celebratory announcement of the sex of a newborn (or fetus), there is almost always an equally critical qualifier, namely, *healthy*. Indeed, my strong breath and normative number of digits marked my movement from thing to human just as much as my vagina did. Borrowing from Butler, I contend that discrete health and ability statuses—not unlike "discrete genders"—"are part of what 'humanizes' individuals within contemporary culture" (522). Objectified knowledges of gender and health, along with their corresponding technologies of division and normalization, have each fundamentally constituted me not only *as* a person, but also as a particular *sort* of person to be recognized, treated, and acted upon in corresponding ways (Foucault 2003b; Rose 1996).

Since my childhood, I have been acutely aware of how the *sort* of gen-

dered subject I was shaped the kind of athlete I could become, and, to some extent, the kind of athlete into which I could make myself shaped the sort of gendered subject I would be. I noticed, early on, how sport involved “dividing practices” whereby my gender classification led to regulated physical separation from my brothers and the allocation to me of equipment, rules, and training regimes that differed from theirs (Foucault 2003b, 126). These gendered sporting divisions only fed my desire to be a better athlete, to show all the boys that I did not play “like a girl.” I was far less aware, however, of how health and ability classifications divided and governed my athletic (and other life) opportunities. My subjectivity as a *healthy* human began in utero and was reproduced through my first breath and the normative timing of my various other developmental “firsts.” I “achieved” enough developmental milestones to successfully pass as a healthy, able-bodied sort of person, the only sort of person that had access to the sports I played. It is plausible that discursive links between health and sport were precisely why my parents kept me in sport, despite the constant injuries that plagued me. I was encouraged to engage with technologies of elite athletics (for example, breath training) so that I would grow up to be a healthy person. I, by contrast, eagerly engaged with technologies of health (for example, “healthy eating”) so as to become a stronger athlete. Only much later did I become aware of the extent to which the mutually constitutive subjectivities and disciplinary regimes of “the healthy” and “the athletic” increasingly narrowed my possible range of actions, rendering me far more governable by the people who would find my healthy, athletic body useful.

*Pressurized oxygen scorches my lungs for the first time: dry bursts burning relief into thirsty tissue and tired muscle. The exhalation is then squeezed out of me by the hands of a caring respiratory therapist. My skin shifts from the blue-white hue of oxygen deprivation to the distinctly red hue of shame. With that stale, mucus-filled, first dependent breath, I begin my voyage as a sickly, revolting gimp. My disabled identity did not prepare me for sickly subjectivity, quite the opposite. Five years earlier, I had been diagnosed into disability through the authoritative pronouncement of a benevolent doctor. My diagnosis followed his confident assertion, “Despite weak lungs, shoulders, and hips, you’re remarkably healthy!” This diagnosis began my voyage as a remarkably healthy inspirational supercrip.*

The bodies, practices, and identities that disability and impairment configure are no more natural or ahistorical than the bodies, practices, and identities that athletics configure. As Shelley Tremain argues, impairment

“is an historically specific effect of knowledge/power,” which divides human variation into categorical types in order to render the people assigned to some of these categories susceptible to the disciplinary interventions of other people, especially people who are regarded as “experts” (2006, 185). My medical diagnosis secured my eligibility for the segregated, diagnosis-only, Paralympic sport world, a world where further classification separated me from my more or less “disabled” peers. My diagnosis also made me subject to a less official and much more insidious set of dividing practices and related disciplinary regimes, which coalesced in the recognizable forms of two different *sorts* of disabled people. One famous inspirational person once explained to me the distinction between the two sorts of disabled people in this way: “There are two kinds of disabled people in the world, those that sit at home complaining and those, like us, who are out there trying to make something positive of themselves.” In other words, there is the remarkably healthy inspirational and independent supercrip that I became at the height of my Paralympic career, and then there is the sickly, dependent, revolting gimp that I became as I transitioned to using tools like oxygen, a backrest, and attendant care.

Dividing practices play out insidiously in the most intimate of spaces and are covertly dispersed throughout many of the most dominant and dangerous institutions, practices, and discourses of our time. Foucault (1980, 2003b) warns us not to conflate this wide dispersal with a top-down, purposefully deployed, ideological intention. Seemingly dominant and powerful normalizing forces (such as the technologies of normalization that constitute inspirational supercrips like me) are nonetheless “fed by innumerable and often conflicting individual aims” (McWhorter 1999, 19). Thus, the outcome of my own subjection was likely not the aim of the people who participated directly in my subjection: the doctor who diagnosed me might simply have been invested in the advancement of his research through my diagnosis, and the athletes who helped shape me into a hyper-able disabled athlete were likely more invested in their own inspirational identity than in mine. My inspirationalization and the reproduction of larger problematic inspirational discourses may have been effects of these various actions, but it is unlikely that they were the shared intentions of the actors. As Barbara Cruickshank explains, “The system and its makers do not create order from above; rather, the messiness of small things makes possible a large system” (1999, 42). This messy, bottom-up production of larger social systems is precisely why Foucault (2003a) calls for an ascending analysis of power. That is, Foucault urges us to trace the way specific intimate rationalities (for example, my teammates trying to pass as

inspirational) merge with particular disciplinary technologies at the level of the individual (say, my self-training to become a hyper-able tool user). He also urges us to follow the way these intimate and individual workings of power may collude with or shift in relation to more widely circulated or deeply institutionalized practices and discourses (for example, widely circulated supercrip stories of overcoming). Even the most seemingly purposeful and capitalist-serving of phenomena (such as liberal discourses of inspirational overcoming) emerge from the bottom up as a messy convergence of often unrelated rationalities, technologies, and discourses. Furthermore, the smallest, seemingly insignificant practices (like my own attempts to go without pressurized oxygen in public) can coalesce in ways that significantly affect the possible life choices and the distribution of life chances for people whom I have yet to meet (see Spade 2011).

*Each breath pierces my diaphragm with violent cramping. I struggle to keep my face relaxed, trying not to let the crowd see me grimace in pain. My weakening respiratory muscles burn from climbing the six stage stairs in my wheelchair in order to accept my “Courage to Overcome” award. As I wait for my cue to speak, I am unsure if I will have the strength to project my voice across the crowd, let alone to project the inspirational image they expect. I look longingly over at the microphone, poised high above a tall, solid, wooden lectern. I could simply stand up and use it. I could have chosen to simply stand up and climb those six stairs by foot. But I choose to remain seated, terrified of standing up like a faker, of passing out like a gimp, of no longer passing as an inspirational supercrip. This doesn’t feel like courage. I long to show real courage: to crush their expectations of wheelchair-boundedness; to point out the disabling, inaccessible stage; to defy the expectation to simply overcome; to show pain. I am given the cue to speak. I open my mouth. I remain silent, due, perhaps, to a lack of oxygen, or courage, or intelligible alternates, or inspiration. I return to the script that I have been told they all want to hear. I say something about the abilities in all of us. I force a smile at the standing ovation but long for the revolution.*

Supercrip subjects and their revolting gimp counterparts are produced through multiple, heterogeneous practices and discourses, many of which employ or collude with liberal forms of government. Within liberal forms of government, one enables and encourages the governed people to act voluntarily, while simultaneously using intricate systems of threats, promises, punishments, and rewards to coerce these same people to “voluntarily” choose actions that are desirable to those who govern (Foucault

2004). As Nikolas Rose argues, liberal governance “has been defined by the problem of how free individuals can be governed such that they enact their freedom appropriately” (1996, 134). The appropriate enactment of freedom for a contemporary western subject is to voluntarily manage (or govern) one’s own bodily functions, capacities, and productive output in ways that comply with the expert advice and normative expectations of medical, financial, and political authorities (Foucault 2004). In other words, liberal forms of government amount to “govern[ing] people by getting them to govern themselves” and thus are useful for creating responsible, self-governing, productive citizens, such as the supercrip (Cruikshank 1999, 39).

The imperative to govern myself long predates my diagnosis as disabled. I came to voluntarily control my own breath, pain reactions, and health practices through repeated disciplinary training and the threat of painful running drills, as well as through the promise, and later the adoption, of athlete subjectivity. As a nondisabled athletic citizen who was racialized as white, however, I was subject to relatively minimal surveillance and discipline because I was largely assumed to be a responsible self-governing citizen. My involvement in sport, in conjunction with my unpathologized body, made me easily readable as someone who had chosen to make herself into a healthy and productive member of society. Once diagnosed, however, I suddenly became a pathological subject who was constantly scrutinized and categorized, disciplined and coerced by experts and passersby alike. I was scrutinized and categorized so that problematic aspects of *subjects like me* might be rendered increasingly intelligible and thus solvable (Rose 1996). I was disciplined and coerced so that I, myself, would increasingly govern the problematic aspects of my self appropriately. I was increasingly scrutinized and disciplined because pathological subjects like me are, it seems, continually suspected of failing at appropriate self-government. We have, too often, proven unable to contain, normalize, and overcome our leaky, spasming, painful, weak, or out-of-control bodies (Clare 1999). We are seemingly too stubborn to adapt to normal disciplinary regimes and training, and thus “selfishly” demand that schools, athletic facilities, and workplaces must be made accessible to us (Withers 2012). We are thought to be too lazy to make ourselves into productive, contributing citizens rather than relying on government funding and support to survive. We are purportedly too irresponsible and incompetent to be trusted to govern ourselves as responsible liberal citizens. We are problematic. We are revolting. We are gimpy. We must be watched, managed, and governed.

To be recognized as a revolting gimp is to be greeted with pity, disgust,

or normalizing advice, if not to be simply ignored. Social discomfort and isolation, however, are not the only effects of this subjection. Disabled subjects who do not pass as self-governing are likely to be written off by doctors, to be unemployed, to live in poverty, to be homeless, and to be incarcerated in prisons, mental hospitals, or nursing homes (Clare 1999; Spade 2011; Withers 2012). Furthermore, disabled subjects who do not pass as self-governing are more likely to find themselves subject(ed) to the intensification of direct government within relations of domination, wherein, for example, experts control how money that belongs to “clients” can be spent (Withers 2012), restrict their freedom of movement (McWhorter 1999), and determine the exact timing of each of their bowel movements (Sullivan 2005). The most readily available strategy for avoiding these relations of near-total domination is, for many, to try to develop one’s capacity to be governed from afar, to become recognized as, and exalted for, governing oneself as a liberal citizen. As a supercrip, my attempts to self-govern, to normalize, to overcome, and to fiercely and spectacularly exhibit my independence and productivity are not motivated merely by heroic virtue, ideological ignorance, or malicious intent. Every disabled subject works within a narrowly constituted field of possible actions. Sometimes it feels as if there are only two choices: control yourself or be totally controlled by other people (McWhorter 1999). As Clare writes, “Supercrip lives inside my body, ready and willing to push the physical limitations, to try the ‘extraordinary,’ because down at the base of the mountain is a nursing home” (1999, 12). The threats and punishments of not (sur)passing as a supercrip are ever present. Unfortunately, passing “successfully” has its costs as well.

*Each breath pierces my diaphragm with violent cramping, even though I get my partner to push me up the ramp to receive my “Woman of Vision” award. I struggle to relax my forced smile. I try not to hide the grimace of pain. This lack of self-discipline is a capacity that I have yet to master. An inspirational video montage of my life plays on the big screen, my politicized sound bites expertly edited out of the final version. I try to stay composed at the crowd’s ovation. I long for the revolution.*

Useful democratic citizens, Cruikshank argues, “are both the effects and the instruments of liberal governance” (1999, 4). That is, the practices, discourses, and subjectivities of useful democratic citizens often inadvertently serve to justify and reproduce the very relations of power to which they are subjected. For the most part, I became a supercrip for self-centered

reasons: because I wanted to continue to be seen as an athlete, because I wanted to maximize my freedom and opportunities, and because I wanted to escape pity and control. Nevertheless, some of my most regrettable supercrip experiences, which occurred when my inspirational story was broadcast across the country, occurred at least in part because of my activism: I wanted to seize the opportunity that the stage afforded in order to try to shift stereotypes of disability and to show that disability is a problem of social injustice, not a problem of problematic bodies. Inevitably and almost invariably, these activist aims backfired. The inspirational supercrip image broadcast through the “Courage to Overcome” award, for example, overshadowed and contradicted the political message that I intended to convey in my acceptance speech.

McWhorter writes, “[S]houldering as much responsibilities for coping with your disabilities only makes it easier for tight-fisted taxpayers to say you don’t need social services at all” (1999, 144). I recognized, early on, that positions of greater political leverage were earned if one demonstrated a capacity to self-govern and inspire. The more leverage I gained, however, the more widely dispersed my inspirational persona became, and therefore the more I undercut the intelligibility of the very changes I hoped to affect, namely, less inaccessibility, isolation, poverty, and pity in the lives of people who experience disability. Through my own unintentional, and even well-intentioned, supercrip actions, I have inadvertently reaffirmed the notion that disability is a problem of other disabled people’s lack of individual will and capacity to self-govern.

Cruikshank argues that practices that aim to produce empowered citizens “link the subjectivity of citizens to their subjection, and link activism to discipline” (1999, 67). That is, practices of empowerment lead people like me to believe that our identities are the cause, not the effect, of our subjection. Practices of empowerment lead us to believe that the activist path to social change involves even greater engagement with the disciplinary practices and the liberal “empowering” regimes that subject us. Insofar as I received that “Courage to Overcome” award, I unintentionally reproduced the legitimacy of the very programs that subjected me as supercrip: the “empowering” disability-sport programs that disciplined my body into increasing healthiness, independence, and self-control, as well as the heroic supercrip stories that had me govern myself into increasingly inspirational forms. Each celebration of me as supercrip is the celebratory reproduction of the very forces that narrowed my range of possible actions, left me increasingly open to government by others, and induced me to govern every aspect of my self.



The inspirationalization and subsequent celebration of the supercrip not only reproduce the forces that govern the inspirational supercrip. They also reinforce the subjectivity of the revolting gimp. Rose (1996) explains:

The language of responsible self-advancement is linked to a new perception of those outside civility—the excluded or marginalized who through willfulness, incapacity or ignorance cannot or will not exercise such responsibility. On the one hand, pathologies are re-individualized, removed from a “social” determination into a moral order, thus providing the basis for new and harsher strategies of surveillance and control of those who, after all, bear the responsibility for their fate within their own hands. (145)

In other words, the inspirational supercrip serves to reproduce, reinforce, and legitimize the subjection, poverty, incarceration, and limited life chances of the people who cannot, or will not, simply overcome. What is perhaps most disconcerting is that throughout my inadvertent participation within the reproduction of these unequal, and often violent, relations of domination, I was often celebrated as an activist or advocate who, by virtue of my supercrip notoriety, was helping to empower the disabled. This dilemma is a problem not unique to disability. As Dean Spade explains, “[T]he hallmarks of neoliberalism are co-optation and incorporations, meaning that the words and ideas of resistance movements are frequently recast to produce results that disserve the initial purposes for which they were deployed” (2011, 34). Through my own frantic attempts to escape revolting gimp status, through my disciplined subjection as an inspirational supercrip, and through my misguided attempts to use inspiration as an activist entry point, I unintentionally reproduced the very structures that, in the long run, would subject my communities and my self.

### *Inspiration Expires*



What I hope this Foucauldian analysis has made clear is that inspirationalization can reproduce extremely dangerous and disabling effects. If, however, the inspirational supercrip is simply written off as a problematic (mis)representation, a hegemonic villain, or an ideological dupe, we have failed to take into account the complex web of ordinary practices and broadly dispersed strategies of government that come to constitute, discipline, coerce, and subject inspirational disabled figures. To understand the

supercrip in this way—that is, as both an effect of and a site for the reproduction of dangerous configurations of power—enables new ways in which to imagine how one might act within, and against, these configurations (see Foucault 1980). Furthermore, if we begin to understand the supercrip in this way, we can begin to understand subjectivity itself as an opportunity and strategy for shifting or reimagining our worlds.

As I have demonstrated through this genealogical auto-ethnography, the self can be a crucial entry point for genealogical critique. The self can be an archive through which one can historicize and problematize the contemporary practices, discourses, and subjectivities of disability that appear most benevolent, natural, or mundane. For Foucault (1995, 2003c), the conscious acting of the self on the self (or, better still, against the self) is at the very heart of ethics. It is a process of critical self-experimentation, fragmentation, and multiplication that offers possibilities for developing different capacities, increasing our range of possible actions, minimizing relations of domination, and bringing new relations and practices into being. Because the subject is such a crucial node in the exercise of power, this critical work on the self is also an engagement with the broader political problems that constitute us (Butler 1988; Foucault 2003c; McWhorter 1999).

In the past few years, my capacity to inspire, in both senses, has diminished. I have taken up the tools of the sickly, engaged in interrelationships of the dependent, and increasingly failed to (sur)pass as a supercrip. I am less and less successful at living in normative ways (Foucault 1997): the ten-hour conference day, the expectation of painless sitting, and the attempted self-propulsion of my wheelchair across the tiniest of grades have become points of inevitable failure. I have undoubtedly come up against some of the more life-threatening systemic violences to which the revolting gimp is subjected. I have become, in some arenas at least, the kind of subject that the state is perfectly happy to “let die” (241). In other arenas, my Paralympic past, my academic present, and the expectation of a cure-encompassed future still protect me. I have come to recognize through this process, and through processes of Foucauldian critique, that contemporary social relations of disability themselves are revolting, not the (revolting) subjects whom they subject. Although I would never downplay the dangers, violences, and relations of domination to which many revolting gimps are subjected, I have come to realize that there may be more room for revolution in the revolting gimp’s gutter than the supercrip’s stage grants me. I have witnessed the way my intermittent failures in the rituals of self-mastery and self-management have created space for improvised strategies

of survival and, with them, new, unanticipated capacities for sensation, connection, experimentation, and subjectification. I have come to believe that there is little transformational potential in the inspirational motto “The crips are overcoming,” and I am increasingly pulled to engage strategically with the war cry “The gimps are revolting!”

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ANNE MCGUIRE



## “Life Worth Defending”

### *Biopolitical Frames of Terror in the War on Autism*

Whose lives count as lives?

—JUDITH BUTLER, *Precarious Life*

In December 2006, following considerable pressure from autism advocacy organizations and parent advocates, the U.S. Senate and House of Representatives unanimously passed a bill officially titled the Combatting Autism Act (S. 843). The bill, which was first introduced by pro-war Republican senator Rick Santorum and signed into law by President George W. Bush (US law 109-416), authorized the allocation, over the course of a five-year period, of close to a billion dollars for biomedical autism research. The money was earmarked especially for research designed to discover cures for autism, treatments for it, and strategies to prevent it. The Combating Autism Act was immediately dubbed—by autism advocates and reporters alike—as the U.S. government’s “war on autism.” “Congress Declares War on Autism,” read an American television network news headline from the winter of 2006 (O’Keefe 2006). “This is a battle plan to win the war against autism,” said federal lobbyist Craig Snyder, who continued by noting that “it’s now the law of the land” (Scelfo and Kantrowitz 2006, para. 6). “This bill is a federal declaration of war on the epidemic of autism,” confirmed John Shestack in an Autism Speaks press release, noting that the bill “creates a congressionally mandated roadmap for a federal assault on autism” (O’Keefe 2006, para. 6). The significance of these speech acts, which link autism and war, extends well beyond their existence as metaphor-laden sound bites. In a historical moment when autism is officially legislated in the United States as an outlaw at large—a state enemy within to be “combated,” “assaulted,” “battled”—the rhetorical appeal to actual wars

in order to motivate social projects designed to eliminate autism from individual and collective life should not remain unexamined.

In this chapter, I trace the contours of a militaristic turn within dominant contemporary forms of autism advocacy, a turn distinguished by advocacy’s reliance on the rhetoric of combat in order to express a material desire for life without autism and, indeed, to achieve this end. By drawing on Foucault’s (1997) discussions of the vitalizing force of biopolitical war, I show how the call to war in the name of (normative) “life” situates the war on autism within a greater cultural context of liberal warfare. It is, therefore, both appropriate and necessary to attend to the “war on autism” alongside a brutally enduring transnational “war on terror,” the latter of which is characterized by the U.S.-led invasion and occupation of Iraq and Afghanistan, by ongoing military operatives in the Middle East, and by heightened domestic surveillance policies and practices. The historical simultaneity of these two wars is not mere happenstance, nor are the striking resonances in their wartime rhetorics, rationalities, and technologies. To the contrary, the war on autism and the war on terror, as well as their respective oppositional figures of terrorist and warrior, are intimately connected, and even dependent on one another, functioning continuously to define, secure, and surveil the borders of a liberal normativity. As a way to reveal how discourses of autism and terror have converged into a shared liberal, biopolitical frame, I begin by examining three recent high-profile autism advocacy campaigns that, on the one hand, cast autism as a terrifying threat to normative life and, on the other, cast advocacy as what must, above all, eliminate this threat.

### *Campaigning Terror*



In the summer of 2005, the Autism Society of America (ASA) unveiled a “new arm to fight autism,” a fundraising initiative called “Getting the Word Out,” which, according to a press release, aimed to “combat the rising statistics of autism diagnosis” (Autism Society of America 2005). As one effort to achieve this end, the ASA launched an elaborate new website, complete with an opening FLASH sequence that featured a gray-scale photograph of a sorrowful child and his seemingly defeated parents. The sequence begins as a small tear is made in the top edge of the photograph. A statement appears: “1 in 166 children are born with it.” The photograph tears a little more, followed by this statement: “24, 000 will be diagnosed with it this year.” The tear extends deeper into the center of the photo-

graph, now beginning to cleave the parents from the child: “It is more common than multiple sclerosis, cystic fibrosis and childhood cancer. Combined.” Tear. “It is growing at a rate of 10–17% each year.” Tear. “Currently there is no cure for it.” As the tear reaches the bottom edge of the photograph, these words appear: “It can tear a family apart.” The sequence ends as the left side of the photograph—the side that displays the image of the parents—is completely torn off and discarded, leaving the tattered image of the boy and these words: “It is . . . autism” (Autism Society of America 2005). This opening sequence of the ASA website in turn delivers us to the inner pages of the website, which provide further information about the origin of torn families and ripped photographs. The section designated as “Autism 101” displays another torn photographic image of what appears to be a young, presumably autistic girl<sup>1</sup> held captive by an unseen, but not unnamed, captor: AUTISM. The adjacent text informs us, “Autism is a neurological disorder that affects the functioning of the brain.” “Autism,” the text continues, “knows no racial, ethnic or social boundaries [and] doesn’t care how much money you make, what kind of lifestyle you lead or what your education level is.” The “Getting the Word Out” campaign, which met with the powerful protests of many disability activists and bloggers,<sup>2</sup> ended in the summer of 2007. Although the campaign was never formally retracted, its controversial website was nevertheless taken down.

In the winter of 2007, only a few months after the ASA website was taken down, New York University’s (NYU’s) Child Studies Center (CSC) launched a similar public awareness campaign called “Ransom Notes.” The campaign, which appeared on billboards, kiosks, and in various online and print media sources, aimed “[to alert] Americans to the silent public health epidemic of children’s mental illness” (New York University Child Study Center 2007b). “We have your son,” declared one advertisement made to look like a typed ransom note. “We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” The note was signed simply “autism.” At the bottom of the note, a statement from NYU was superimposed. The statement reads, “Don’t let a psychiatric disorder take your child. The NYU Child Study Center is dedicated to giving children back their childhood by preventing, identifying and treating psychiatric and learning disorders” (New York University Child Study Center 2007a). When, soon after the “Ransom Notes” campaign was launched, an outraged autistic community engaged in political action against it, NYU publicly retracted the claims made in the campaign (New York University Child Study Center 2008).

In the fall of 2009, a year and a half after the “Ransom Notes” campaign was terminated, Autism Speaks introduced a strikingly similar initiative, this time in the form of the short film *I Am Autism* (*I Am Autism* 2009). Written by Grammy-nominated songwriter Billy Mann and directed by Academy Award winner Alfonso Cuarón—both of whom are parents of autistic children—the film premiered to an audience of over 150 political dignitaries from around the world at the second meeting of World Focus on Autism, the international meeting that Autism Speaks holds annually in order to address “the global crisis of autism” (Autism Speaks 2009b). The film, which features actual home video footage of individual autistic people (mostly children), is divided into two highly choreographed parts.<sup>3</sup> In the first part of the film, the video images are tied together by an ominous horror-film-style soundtrack, which includes hollow echoes of children’s cries and a deep and sinister voice of “autism.” The voice rumbles:

I am autism. I’m visible in your children, but if I can help it, I am invisible to you until it’s too late. I know where you live, and guess what? I live there too. I hover around all of you. I know no color barrier, no religion, no morality, no currency. . . . I move very quickly. I work faster than pediatric AIDS, cancer, and diabetes combined. . . . And if you are happily married, I will make sure that your marriage fails. Your money will fall into my hands and I will bankrupt you for my own self-gain. I don’t sleep, so I make sure you don’t either. I will make it virtually impossible for your family to easily attend a temple, a birthday party, a public park, without a struggle, without embarrassment, without pain. . . . I am autism. I have no interest in right or wrong. . . . I will plot to rob you of your children and your dreams. . . . And the truth is, I am still winning, and you are scared, and you should be. I am autism. You ignored me. That was a mistake. (*I Am Autism* 2009)

The second part of the film shifts dramatically in tone and tempo. The autistic people who had appeared alone only moments earlier in the film can now be seen surrounded by family. The hollow cries of children have been replaced with full-bodied giggles, the eerie percussion has been traded for the upbeat tempo of the plucking of a guitar, and the singular, menacing voice called “autism” has been silenced by a chorus of voices called “advocacy.”

We will spend every waking hour trying to weaken you. . . . We are Qatar. We are the United Kingdom. We are the United States. We are China. We are Argentina. We are Russia. We are the European Union. We are the United Nations. . . . We are coming together in all climates.



We call on all faiths. We search with technology and voodoo and prayer and herbs, genetic studies and a growing awareness you never anticipated. . . . We speak the only language that matters: Love for our children. Our capacity to love is greater than your capacity to overwhelm. . . . We are a community of warriors. We have a voice. . . . You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands? . . . Autism, if you are not scared, you should be. (*I Am Autism* 2009)

The “I Am Autism” campaign, like the other advocacy campaigns that I have discussed, was met with an eruption of protest from a rapidly expanding neurodiversity movement (Autism Self Advocacy Network 2009). In response to the overwhelmingly negative reaction, Autism Speaks removed the video link to the *I Am Autism* film from its website almost immediately.

### *Devolving Autisms, Evolving Advocacies*



Taken together, these advocacy initiatives—which are only three examples of a host of similar initiatives—provide a composite sketch of a very particular enemy figure. In all three campaigns, the figure of autism is depicted as terrifying and terrorizing: isolating people from their loved ones, ripping apart the fabric of the family, holding kids captive. We are introduced to an autism that is faceless, hidden and ubiquitous, lethal, and out of control, one part biology—striking at the body indiscriminately and spreading quickly—and one part (a)morality—cruel and uncaring, unmoved by the fiercely guarded social boundaries of privilege or position. Emerging out of a domestic background image of (normative, nuclear) family and childhood innocence, autism is delivered to us as an anthropomorphized threat: half metaphor, half corporeal, entirely real. In opposition to this terrifying and terrorizing figure of autism, a very particular figuration of autism advocacy materializes. The figure of the advocate is framed as a witness to autism’s terrible deeds. Captive children and torn families generate the need for an advocate who must take action not *for* autism, as the term *autism advocacy* might seem to suggest, but rather *against* it. Performing a dangerous split between autism and what is presumed to be an otherwise non-autistic person, the campaigns figure the advocate as someone who must embark on a kind of reconnaissance mission aimed at “recovering” a normative child from behind autism’s enemy lines (McGuire 2011a). As per “Ransom Notes,” the advocate must return children to a normative child-

hood by “identifying” autism, “treating” its abnormalcy, and thereby “preventing” the future harm that its presence invariably promises.

Certainly, the three campaigns—“Ransom Notes,” “Getting the Word Out,” and “I Am Autism”—are similar; nevertheless, we can note significant differences between them. For example, although the “Getting the Word Out” campaign confronts us with a distant enemy figure that targets children in general, the “Ransom Notes” campaign brings autism’s crimes closer to home by specifying its target audience: the notes are addressed to a “you.” This shift from “enemy of children in general” to “your enemy” re-configures the advocate from a neutral witness who is charged with the task of helping to spread the word about autism’s terrifying deeds to an invested victim who must protect and defend him- or herself from this figure and its deeds. “I Am Autism,” too, makes some key changes in the narration of the terrorizing figure of autism and its terrifying transgressions. Although Cuarón’s *I Am Autism* continues to ensure a personal tie with the viewer advocate by continuing to address a “you,” the film is narrated from autism’s own perspective and, in this way, offers the viewer an intimate glance at the inner machinations of the mind of this monstrous figure, drawing the “you” even closer to it. In Cuarón’s film, the figure of autism speaks (pun intended). Although photographs and notes tell us little about its proximity, the voice of autism is always nearby. Autism, which retains the shape of a hostage taker that it took in previous campaigns, has now taken on the additional dimensions of a kind of predator. Autism is next door or even in your very home. It is watching your family movies and intimately, malevolently, plotting its next transgression. Most disturbingly, in *I Am Autism* we are confronted with an autism that is growing bolder; its words do not merely address the viewer advocate, but rather they taunt it. “I’m still winning,” provokes autism, “and you are scared.” This figure of autism formulates a threat that is, simultaneously, a challenge, a challenge that shapes advocacy into an adversarial opponent. Note the depiction of the figure of autism as devolving in the three campaigns, that is, note its depiction as an entity that continually grows bolder, hits harder, and moves closer. Note also how, as the figure of autism devolves, the figure of the advocate evolves, moving from witness to victim, from victim to victim no longer. In short, the figure of the advocate is transformed into a militant warrior who not only (reactively) defends and protects but also (actively and even preemptively) engages in battle.

As indicated above, many people came together and declared these figurations of autism to be inaccurate, inflammatory, oppressive, and dangerous. In order to resist the propagation of a terrorizing figure of autism and

a militant figure of advocacy, many of us claimed that these campaigns were the product of a case of mistaken identity. Autism is, we said, going down for a crime it did not commit (Kras 2010; McGuire 2011a). Evidently, our tactics thus far have, for some reason, not been effective. For just as one campaign is retracted, another, almost identical campaign is launched, and this is a recurring phenomenon (see, for example, these other, more recent campaigns, which again narrate autism as a terrifying figure: Autism Awareness Australia 2010; Autism Speaks 2010; and National Autism Association 2010). Although we must continue to point to mis-characterizations of autism, we must also ask *how* such mischaracterizations continue to be made possible. In the midst of these repeated cycles of reaction against mis-characterizations and retractions of them, we should ask what new strategies of resistance can be adopted in order to *both* contest and permanently dislodge this materially and ideologically damaging figuration of an autism enemy. How has autism been framed to ensure that it goes down for a crime it has not committed? In the next section of this chapter, I use framing theory and Michel Foucault's discussions of biopower in order to address these questions. In particular, I demonstrate how dominant contemporary discourses of autism and advocacy are surrounded by, and contained by, historically and culturally specific frames of terror.

*Framing Autism: Biopolitics and the  
Liberal Rule of Life*



Following the work of Erving Goffman (1986), Judith Butler (2009), Trinh T. Minh-ha (1992) and others interested in the interpretive practices of framing, I use the concept of “the frame” to denote that which marks the limits of a scene, the shifting and contingent epistemological scaffolding that is logically and temporally prior to a phenomenal field (Minh-ha 1992; Titchkosky 2007). A condition of appearance, the frame also and necessarily conditions appearances; a frame anticipates a phenomenon, collects it, renders it intelligible, and allows it to appear as it does. Like the scene of a painting, or any other scene for that matter, the “scene” of autism advocacy is no doubt conditioned by multiple frames, frames that are historical, geopolitical, economic, and ethical in character, frames of charity, of biology, of love, and of war, frames that are integral to the scene they frame and that function to direct and so regulate the ways in which we come to regard the phenomena of autism. Significantly, however, the range of cultural frames that encase contemporary autism advocacy discourses very often escape

our critical attention, uniting with—and so disappearing into—the colorful, taken-for-granted landscape of everyday life. As the variety of possible interpretive frames diminishes, dominant ways in which to regard autism and advocacy become rendered as natural, given, and self-evident, transformed from their status as sociopolitical constructs to the way that things naturally are and have always been. Because processes of framing typically function normatively, that is to say, because a given frame appears only to disappear through a process of naturalization, regulating space and perception in ways that efface its own construction, to pay critical attention to the multiple frames that condition the phenomenon of autism advocacy today is a disruptive act indeed. “To call the frame into question,” writes Butler, “is to show that the frame never quite contained the scene it was meant to limn, that something was already outside, which made the very sense of the inside possible, recognizable” (Butler 2009, 9). In the midst of disappearing frames and naturalized, taken-for-granted understandings, the critical task, according to Butler, is to connect the scene before us—in this case, the scene of autism advocacy and the figures that dwell within this scene—to the often-taken-for-granted interpretive frames that contain the scene and the figures within it, giving them shape and possibility.

Since the appearance of any given image, object, or other phenomenon relies on a prior frame, the task of the cultural critic is to give an account of the kinds of frames that are installed around certain scenes or certain figures, as well as an account of how these frames differentially allocate and deny power and privilege. Butler (2009, 8) reminds us:

“To be framed” is a complex phrase in English, a picture is framed, but so too is a criminal (by the police) or an innocent person (by someone nefarious, often the police), so that to be framed is to be set up, or to have evidence planted against one that ultimately “proves” one’s guilt. . . . [If] one is “framed,” then a frame is constructed around one’s deeds such that one’s guilty status becomes the viewer’s inevitable conclusion.

Although contesting the validity or accuracy of a given figuration often provokes an infinite regress of empirical debate, to think of the figure as framed—to “frame the frame,” as Minh-ha (1992) puts it—both accounts for the situated ways in which certain bodies are produced as always and already guilty *and* opens up space in which to critically engage the multiple interpretive frames that work to structure our modes of recognition such that, as Butler (2009, 8) notes, a “guilty status becomes [an] inevitable conclusion.”

Liberal biopolitics is one powerful interpretive frame that structures the war on autism and the militaristic turn in autism advocacy more broadly. If we were to critically attend to the liberal biopolitical and other frames that currently encase autism advocacy discourses, we would be better positioned to understand how autism is made into a figure of terror, as well as to understand how the subsequent militaristic advocacy response to it is naturalized and normalized.

In a lecture delivered at the Collège de France on March 17, 1976, Foucault argued that the eighteenth century witnessed an important transformation in the way power came to be exercised over the subject. With the rise of liberalism (and its attendant investments in notions of progress and the overall betterment of human life), a new form of power materialized, a “biopower” concerned with the management of “life itself” (Foucault 1997, 239). Foucault grounded this concept of biopower against the backdrop of a classical theory of sovereignty. Whereas the power of the sovereign is, in Foucault’s articulation, the power to “take life or let live,” biopower is the power to “make live” and “let die” (241). The distinction between a sovereign power that “lets live” and a biopolitical power that “makes live” is an important one. Under sovereign rule, life is a privilege of the subject: one lives because the sovereign has not yet exercised his power to kill. Whereas sovereign power is essentially a morbid power defined by, and contingent upon, the sovereign’s right to inflict death, biopower is a vital power with the principal vocation of making life live. Biopower targets life so as to improve it, optimize it, and above all ensure it. In the here and now of liberalism, “to live” (and, of course, here we must read “to live better” according to normative liberal standards and values) is the rule.

Technologies of biopower take as their referent the living biological individual, but only insofar as this individual lives in relation to—and thus alters and affects—the overall life of a greater living biological entity: the “vitality” of the species. As the “population” (itself a product of biopower) emerges as a political and economic problem, biopower produces a host of regulatory mechanisms—for example, health statistics, birth-to-death ratios, and rates of illness and disability—whose functions are to measure, monitor, evaluate, and ultimately manipulate coefficients of life in order to secure and even augment the “good life” of the (liberal) social whole. As these regulatory mechanisms work to “establish a sort of homeostasis” of the social body, they simultaneously normalize populations and condition the emergence, and indeed the proliferation, of categories of abnormalcy, problem populations in need of normative interventions (Foucault 1997, 246). This hyper-attention to, and meticulous classification of, species

life—this “fragment[ation],” in Foucault’s words, “of the field of the biological”—has altered modern conceptualizations of the categories of life and death (255). Under biopower, life has been extended into a kind of vital spectrum, with many gradations.

There are also, it follows, many shades of death. Foucault describes a “gradual disqualification of death” under biopolitical rule and, along with it, a shift in the overall conceptualization of the category of death (Foucault 1997, 247). “Death,” he writes, is “no longer something that swoop[s] down on life,” but rather is “now something permanent, something that slips into life, perpetually gnaws at it, diminishes it, weakens it” (244). Death is no longer that which takes life all at once but rather a kind of pathology that penetrates life’s frontiers. Death infiltrates, spreads, wastes—even terrorizes. It is the murky underbelly of vitality, the expression of life’s absences, a kind of biopolitical non-life or “necropolitics,” to use Achille Mbembe’s (2003) term. Under a liberal rule of life, the threat of this relationally negative space of non-life is (and, indeed, must be) understood and articulated in and through the terms and tropes of vital (biological) invasion in and through discourses of pathology. This re-signification of death as a pathological relation of life rationalizes certain forms of human difference as vital and, as such, in need of protection and preservation, while simultaneously casting other forms of human difference as life threatening and, as such, in need of neutralization and/or elimination.

Let us return now to the contemporary scene of autism advocacy, a scene that is born of and framed by liberalism and its biopolitical rule of life. It is not a coincidence that the emergence of the diagnostic category of autism coincides with the rise of liberal governmentalities (on the “diagnostic style of reasoning” and liberal governmentality, see Tremain 2010). Indeed, liberal concerns with the contours of life—and the resultant proliferation of diagnostic categories under this regime—have made possible dominant contemporary versions of autism and advocacy. While liberalism shapes life as conditional, autism emerges as one of life’s conditions. As I have argued, autism is predominantly framed as always and already guilty of terrorizing and terrifying; that is, autism, though not necessarily guilty of taking away life per se, is rather guilty of infiltrating it, destroying it, ruining it, “spoiling” it (Goffman 1963). Autism is, time and again, conceived of as nothing other than an undesirable and even dangerous individual biological pathology. The evidence is in, and it is damning: bad biology, miswired brains, devolving development, histories of red flags. As autism is narrated as a threatening individual condition, it simultaneously materializes as a life-threatening condition of the normative whole; that is, autism is

framed as a kind of morbid public enemy targeting non-autistic “innocents”—a “tearer” of families, a stealer of children. This notion of autism as a public threat is further underscored by the fact that it is commonly articulated in epidemiological terms. Autism is framed as a spreading pathology that takes hold of normative bodies and minds and moves through populations, working faster “than AIDS, cancer, and diabetes combined” (to borrow a very commonly evoked phrase). In short, autism is framed as an “epidemic” that threatens normative liberal versions of collective life in at least two ways: first, as the diminishment of the “good life” of a middle-class nuclear family, evidenced in high rates of divorce, depleted bank accounts, disrupted leisure activities, and ruined birthday parties; and, second, as the erosion of the vital life of liberal society as a whole, manifested in social burdens, costly health care needs, the disappearance of independence, and so on. In these ways, a “life with autism”—conceived of in the sense of both the individual “with autism” and the collective “with autism”—is ushered into contemporary intelligibility as a kind of biopolitical death. Framed like this, that is, autism’s “guilty status” is surely *made* an “inevitable conclusion.” And, yes, there is plenty of guilt to go around.

Insofar as autism and its advocate are invariably tied together in discourses of advocacy, the frames that present autism as always and already guilty of life-threatening acts shore up the advocate as always and already suspect. Indeed, the contemporary figure of the autism advocate is continuously framed as potentially guilty of failing to learn the signs, potentially guilty of failing to vigilantly watch for “red flags,” potentially guilty of, in other words, aiding and abetting an already guilty autism and, in so doing, becoming complicit in autism’s crimes against (liberal versions of) life (McGuire 2011a). *Vis-à-vis* guilty and potentially guilty figures that threaten the frontiers of liberal life, a whole host of security mechanisms must be erected to safeguard life, protect it, and, indeed, ensure it by keeping non-normative (autistic) life at bay. Whereas biopower frames autism as a pathological threat that must be neutralized or eliminated for the “good” or the “health” of normative liberal life, advocacy materializes within the terms of biopower as that which—at all costs—must protect, preserve, and/or recover non-autism. The work of autism advocacy thus becomes the normative and normalizing work of (biological) securitization, including the search for autism’s “red flags” and calculation of its “odds” of occurrence (McGuire 2011a, 2011b). When breaches in security happen, as they invariably do—that is, when the red flags go up, when the alarm sounds, when the odds close in, when, in other words, the imagined

frontiers of normative life are penetrated and this life is understood to be under attack—advocacy must go to war.

*Biopolitical War and the Racist/Ableist Constitution  
of “Life Worth Defending”*

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There can be little doubt that we live in the midst of a global—and globalizing—war on autism. The notion that autism ought to be eliminated from human life is written into U.S. law, institutionalized in public policy, and sung throughout popular culture. Indeed, we find ourselves in a social and historical context where doctors, professional athletes, celebrities, politicians, journalists, parents, and concerned civilians from around the world come together “against autism,” a context in which we can walk, run, row, fish, shop, or take a cruise to “fight autism,” read up on the latest research study “taking aim at autism” (York University 2010), or tune in as celebrity advocate Jenny McCarthy—author of the *New York Times* best-selling book on parenting autistic children called *Mother Warriors*—teams up with World Wrestling Entertainment for an “autism smackdown.” Although these examples of how war is waged on autism are overt and glaring, there are many other, more covert ways in which this war is waged. Everyday enactments of autism advocacy cast autism as a pathological threat to normative life and call up advocacy as that which must eliminate this threat. Of course, our historical moment has (glaringly) given birth to the “war on terror,” in addition to producing this “war on autism.” For the remainder of this chapter, I consider the contemporaneous existence and persistence of these “wars” and suggest that the simultaneity of their appearance is not mere historical happenstance. To the contrary, the war on autism and the war on terror—and their resonant oppositional figures of autism/terrorism versus advocate/warrior—are intimately connected and even dependent on one another inasmuch as they both share a very particular—that is, a liberal, biopolitical—war frame.

In order to better understand the liberal frames of war that surround, condition, and connect the war on autism and the war on terror, we must first ask how it is possible to wage war, and thus expose life to the possibility of harm, under a biopolitics in which “life” is given primary value. Under a politics that privileges and even enforces life, war seems to be counterproductive, seems itself to be a transgression of the vital rule. Foucault reminds us that liberal war and the harm it invariably causes are possible, and can only be made possible, when waged in the name of life (Foucault 1997, 256).



As (normative) “life itself” becomes (under liberalism) both what is of value and what is at stake, war and its inherent violence, must emerge as a kind of “vital” force charged with the task of ensuring that *particular kinds* of “life” persist and thrive (Foucault 1990, 40). This vital technology of liberal war, Foucault argues, is and must be conceptualized in racist terms (Foucault 1997, 257). That is, Foucault proposes racism not as an ideological commitment or mere set of biases and attitudes but rather as, in his words, “a way of introducing a break into the domain of life that is under power’s control” (254). For Foucault, the liberal process of breaking up and marking out vital and pathological types, through the hierarchical organization of “viable” and “non-viable” ways of living humanness, is the primary technology of contemporary racism.

Nowhere is this vital logic more striking than in the wartime rhetoric of former U.S. president George W. Bush (Reid 2006; Dillon and Reid 2009; Butler 2009). Let us consider, for example, how biopolitical logics structure the following speech that Bush delivered on March 19, 2004. In commemoration of the one-year anniversary of the U.S.-led war in Iraq—a particularly bloody year of war with a death toll of more than one hundred thousand (Roberts et al. 2004)—Bush offered the American public a few remarks about the value of life. “There is a dividing line in our world,” he said,

not between nations, and not between religions or cultures, but a dividing line separating two visions of justice and the value of life. On a tape claiming responsibility for the atrocities in Madrid, a man is heard to say, “We choose death, while you choose life.” We don’t know if this is the voice of the actual killers, but we do know it expresses the creed of the enemy. It is a mind-set that rejoices in suicide, incites murder, and celebrates every death we mourn. And we who stand on the other side of the line must be equally clear and certain of our convictions. We do love life, the life given to us and to all. We believe in the values that uphold the dignity of life, tolerance, and freedom, and the right of conscience. And we know that this way of life is worth defending. There is no neutral ground . . . in the fight between civilization and terror, because there is no neutral ground between good and evil, freedom and slavery, and life and death. (Bush 2004, 411)

Bush’s speech cut a dividing line deep into the world, splitting it into two parts—*allies/us* and *enemies/them*—that are distinguished, not coincidentally, by oppositional visions and values with respect to life. Bush sculpted one world—presumably, the “we” of America and its allies—in

biopolitical terms as an essentially “living” or “vital” world populated by thriving figures who “love life, the life given to us and to all.” These “ally” figures perform and confirm their vitality by their adherence to liberal norms and values: “life” was additionally constituted in Bush’s speech as “civilized,” “free,” “tolerant,” and so on. Meanwhile, the *other* world—the “they” of al-Qaeda, consolidated in the racialized figuration of the “Muslim terrorist”—was framed as that which falls outside liberal norms and values or even exists in threatening opposition to these norms and values. Bush framed a “we” that is “civilized” and “free” against a “they” that is “terrorist,” “enslaved,” and so on. In a racist insertion of a break in the continuum of life, that is, Bush’s speech conjured and shaped a Middle Eastern “death world” (Mbembe 2003; Puar 2007) populated with pathologically morbid Muslim terrorists who “[rejoice] in suicide, [incite] murder, and [celebrate] every death we mourn.” Where Bush’s “we” makes live, his “they” takes life. While his “we” is always (or at least until expelled) inside the rule of life, his “they” is always, firstly, guilty of transgression of the rule of life.

Bush, in referring to a tape released by a group that claimed responsibility for the 2004 Madrid train bombings, described a malignant voice that issued terrifying threats to (normative, liberal versions of) life and, furthermore, told us that a man’s voice can be heard on the tape saying, “We choose death, while you choose life.” “We do not know if this is the voice of the actual killers,” the president admitted, reminding us that ultimately this burden of proof did not matter. That is, it did not matter whether or not this voice was the voice of the actual culprit behind the bombings, for within Bush’s liberal frame of life and death the voice on the tape—cathected to death—materialized from the start as breaking the rule of life. The voice on the tape was the life-draining voice of the already guilty, which spoke a (racially inflected) “creed of the enemy.” Under a liberal biopolitics, where transgressions of the rule of (normative) life are encoded not merely as deviant but also as pathological and indeed as life threatening, this voice spoke the need for its own elimination. From within biopolitical frames of war, American military invasion and occupation were henceforth re-encoded as (life-saving) threat elimination in terms of which the casualties that these operations invariably produced, and continue to produce, were and are framed as “necessary violence” (Foucault 1997; Butler 2009).

There is something familiar in the malignant voice of Bush’s speech, a voice that utters terrifying threats of biopolitical death. It is faceless, hidden, lethal, out of control. Recall that the terrifying and terrorizing figure

of autism, too, effectively materializes in speech acts that threaten the normative (social and individual) body. Autism, too, is framed as always and already guilty of speaking a “creed of the enemy” and, as such, calling for its own elimination, its own eradication. The figure of autism, much like the figure of the terrorist—or perhaps, more precisely, *alongside* this figure—is made the necessary casualty of a vital and vitalizing war.

Let us more closely note, therefore, the striking resonances between the rhetorical devices that have given shape to, and continue to give shape to, both the war on terror and the war on autism, as well as give shape to the particular ally and enemy figures that these war stories generate. For the startling ease with which the wartime rhetoric of the war on terror blends with the dominant rhetoric of autism advocacy is instructive. The racist figuration of a death-driven Muslim terrorist and the ableist figuration of a terrifying autism are tied together in a tale of terror drawn from, and made intelligible within, a historically and politically specific discursive formation that ascendant liberal versions of life govern. In the next section, therefore, I conclude this chapter by considering Bush’s characterization of the post-9/11 terrorist “enemy” and the construction of a necessary response to this enemy against the autism/advocacy narrative put forward in the *I Am Autism* film. In so doing, my intent is not to make a simple analogy or comparison between the respective figurations of terrorists and warriors, but rather to attend to the shared (racist/ableist) biopolitical war frame that pulls these figures together and allows them to appear as they do. Theoretical and political acknowledgment of the continuities between categories of disability and race under biopower holds important implications for critical analysis and intervention: attention to the biopolitical production of race and racism can clarify understandings of disability and systems of ableism (and vice versa). Insofar as biopower frames the category of autism (and indeed the category of disability more broadly) as a primary threat to (normative) species life, the category of autism has become as crucial a component of modern forms of racism as the category of race has become to modern technologies of ableism (for more on the biopolitical continuities between categories of disability and race, see McWhorter 2009; Tremain 2012; and Chen 2012). This process of clarification is made all the more evident as we pull apart and analyze the biopolitical logics that underpin liberal warfare. Biopower functions to both disable *and* racialize the figure of the terrorist and the figure of autism, producing these figures as the proper targets (and necessary casualties) of wars aimed to “eliminate . . . biological threat” so as to “improve . . . the species or race” (Foucault 1997, 256). In this way, the

“war on autism” and “the war on terror” can be read as biopolitical wars that are continuous with each other and whose shared aim is to define, preserve, and secure the borders of a normative homeland (or liberal versions of it) by marking out threatening types that (or rather *who*) require absolute eradication in the name of life of the whole.

*Pathologized Enemies and Vitalized Allies*



Merely a day after September 11, 2001, in what was a watershed moment in the formation of contemporary understandings of terrorism, Bush delivered a now infamous speech in which he characterized the figural shape of the terrorist. He said, “We are facing a different enemy than we have ever faced.” Then he continued:

This enemy hides in shadows, and has no regard for human life. This is an enemy who preys on innocent and unsuspecting people, runs for cover. But it won’t be able to run for cover forever. This is an enemy that tries to hide. But it won’t be able to hide forever. This is an enemy that thinks its harbors are safe. But they won’t be safe forever. (Bush 2001, 1100)

This figure is a new, or at least different, kind of enemy whose threatening character is understood in terms of a particular kind of pathological threat, a threat that hides, spreads, circulates, infiltrates, and gets closer to home. Out of, and in relation to, this ostensibly different kind of enemy emerged a different kind of allied response. “The United States of America,” continued Bush:

will use all our resources to conquer this enemy. We will rally the world. We will be patient, we will be focused, and we will be steadfast in our determination. . . . We will not allow this enemy to win the war by changing our way of life or restricting our freedoms. America is united. The freedom-loving nations of the world stand by our side. This will be a monumental struggle of good versus evil, but good will prevail. (1100)

With these remarks, Bush referenced a terrorist enemy that could be anywhere, blending in, moving unnoticed through borders in diffuse global networks, laying low in deviant “cells.” This figuration of the terrorist that travels in (to borrow from Puar’s genealogy of the terrorist subject) “rhizo-

mic, cell-driven, non-national, transnational networks that have no self-evident beginning or finite end” (2007, 52) is understood by way of racist/orientalist notions of infiltration and contamination and, therefore, by way of an inherently ableist conception of biological contagion. Puar demonstrates how the characterization of the movement of terror along the representational lines of cellular contagion is “often sublimated (against the foil of the western liberal rational subject) through the story of individual responsibility and personal pathology” (52). The cellular, epidemic-like movement of the terrorist is reified, in other words, by the notion of a pathological biomedical impairment that the terrorist subject possesses (is possessed by?). Acts of terror are dominantly framed—explicitly and implicitly—as nothing more than, nor anything less than, both the destructive effects of the individual (psycho)pathology of the Muslim terrorist and the collective (psycho)pathology of a Muslim “death world.” The “creed of the enemy” is not a doctrine or an ideology per se (as Bush articulates in his 2004 speech), but rather a death-driven “mind-set.” Indeed, the minds and movements of the terrorist have been psychologized through and through (for example, see Crenshaw 2000; Borum 2004; Horgan 2005; and Post 2008). Terrorism, in general, has been postulated to be a result of a terrorist individual’s “death-confronting behaviour” born of a “fragmented psychosocial identity,” “depressive tendencies,” “lack of empathy,” and so on (Hudson 1999, 25–28), while specific “acts of terror” have even been attributed to an unsettling and very much pathological “extranormativity” (31).

Significantly, the notion that the pathology that threatens the frontiers of the liberal (life) world might not be immediately apparent is precisely what has materialized and ultimately consolidated the Muslim terrorist as so utterly terrifying. Bush’s enemy figure possesses the dangerous combination of a (nearly) normative outward appearance and a pathological death-driven inner impairment. Of course, the figure of autism is framed as possessing/possessed by a wide range of pathological impairments—biomedical pathologies such as “mis-wired” brains (as we have seen) and bad genes that lead, inevitably, to deviant behaviors. Alongside the figure of the terrorist, the terrifying behaviors associated with the figure of autism are the result of a “lack of empathy” or “mindblindness” (Baron-Cohen 1997; McGuire and Michalko 2011). Time and again, the threat of autism is narrated, precisely, in terms of its *invisibility*. The story of autism also represents it as a kind of invisible pathology that *spreads*, a pathology that infiltrates normative populations in an epidemiological, cellular fashion, an epidemic “work[ing] faster than pediatric AIDS, cancer and diabetes combined.” Autism is framed as knowing no borders or barriers, as learning

languages, infiltrating homes, moving next door, and hiding in otherwise normative bodies. Figures of terror, in Bush's words, "hide in shadows." They are "invisible until it is too late," as the voice of autism in Cuarón's film warns. Betrayed by pathological movements and behaviors, the contemporary figure of terror emerges as a *threat* to species life whose pathological character is understood as biologically abnormal, as well as essentially *amoral*. Whereas, for example, a pathological inner impairment drives the figure of the Muslim terrorist to perform acts of (in Bush's words) "evil," to prey "on innocent and unsuspecting people," and to "rejoice in suicide" and "celebrate death," notions of autism as a neurological disorder give shape to a figure who stalks families, plots to rob (liberal) hopes and dreams, takes and holds kids hostage, and does so with—as per *I am Autism*—"no interest in right or wrong," "no morality."

While discourses of terror shape the biopolitical enemy as invisible, encroaching, life-threatening, and amoral, they also work to delimit the terms of responses to it as both necessary and moral. *Vis-à-vis* a death-driven enemy, a life-loving, and life-saving allied warrior is born. Confronted with an enemy that hides in plain sight, the "ally" must increase its surveillance techniques, fortify its borders, and hone its technologies of war. Said Bush to terrorism, "The United States of America will use all our resources to conquer this enemy"; "we will be patient, we will be focused, and we will be steadfast in our determination." We will watch where you "run," find where you "hide," and uncover your "safe harbors." Said the autism advocates to autism, "We will not rest until you do," we will search for you "with technology and voodoo, prayer and herbs, genetic studies, and a growing awareness you never anticipated," we will "knock down" your "walls" with our "bare hands," and "if you are not scared, you should be."

Faced with a life-threatening global network of enemies—a moving and hidden pathology that contaminates and spreads through the social and individual body—allied soldiers and civilians draw together in the establishment of a homogeneous, normative "we." The establishment of biopolitical threat—whether figured in the shape of autism or a Muslim terrorist—secures a collective "we" with a kind of vital and vitalizing patriotism. "America is united," stated Bush, "and we will rally the world," for "the freedom-loving nations of the world stand by our side." "We are a community of warriors," said the Autism Speaks advocates. "We are Qatar. We are the United Kingdom. We are the United States. We are China. We are Argentina. We are Russia. We are the European Union. We are the United Nations." It should not be surprising that both the "war on autism" and the "war on terror" evoke this kind of loving patriotic response. Indeed,

the very notion of patriotism betrays the intermingling of the geopolitical and the biological. Patriotism—the love of and for the *patris*, or “fatherland”—is devotion to a *living* nation, a “homeland” that also constitutes a lineage, an inheritance, a family, a body. Faced with the life-threatening figuration of a terrifying and terrorizing enemy (be this enemy the figure of the terrorist or the figure of autism), the “ally” (that is, the proper advocate, respectable citizen, good soldier, etc.) is constrained as a militant warrior, is restrained as the fiercely loving protector and defender of the borders construed as a kind of normative homeland (which is at once a political paradigm, a nation, a family, a child), and is charged with the task of securing, and indeed ensuring, normative life no matter what the cost and regardless of the casualties.

Insofar as the “war on autism” upholds the value of normative liberal versions of life and indeed works to ensure their value within the borders of the nation, it reifies the need to protect “this [normative white, patriarchal, able-bodied, middle-class, heterosexual] way of life” from other terrifying and terrorizing external threats. The implication is striking: the figure of autism galvanizes the “war on terror” just as the figure of the terrorist bolsters the “war on autism.” The intermingling of political agendas can be gleaned in the *I Am Autism* film, for example, insofar as Qatar—a state with significant political and military ties to the United States and the home of the largest U.S. air base in the Middle Eastern region, as well as a host of other military installations—is the sole Muslim-majority country incorporated in the vital fold of nations that the advocacy organization Autism Speaks has united against autism. With such political investments in mind, it becomes even more crucial to acknowledge the materiality of the production and circulation of terror figures. Shaped by metaphor and rhetoric, such figures usher particular bodies—read actual disabled and/or racialized people—into recognition as always and already guilty of terrorizing life. Although biopolitical war frames function to govern the ways in which we come to regard all embodied movements and behaviors as potentially terrifying and terrorizing, some “racialized disabled” bodies or “disabled racialized” bodies are differentially positioned within such frames so as to appear as always and already deviant: death driven and life threatening (Watts and Erevelles 2004). The cultural understanding of bodies as legible sites that are always in danger of betraying the profile of the terror figure results in the proliferation of security mechanisms and the installment of a wide range of surveillance techniques at normative borderlands and state frontiers, from airport security lines to prenatal screening, from threat assessments to behavioral assessments, from terrorist watch lists to autism

registries and identity cards. In this way, biopolitical frames render particular bodies differentially and disproportionately vulnerable to intervention, detention, and incarceration, as well as other violations and violences enacted in the name of life (McGuire 2011a, 2011b; Butler 2009).

#### NOTES

1. As Kathleen Seidel importantly notes on her (now defunct) blog *Neurodiversity: A Weblog*, "We do not know whether the girl is afraid of the photographer, or whether she wishes to be photographed. We do not know whether she has been paid for the use of her image" (Seidel 2005, para. 8).

2. One of the most notable of these acts of resistance was, perhaps, Amanda Baggs's brilliantly disruptive counter-campaign "Getting the Truth Out" (Baggs 2005).

3. An Autism Speaks press release entitled "Do You Want to Be in a World Autism Video?" issued an appeal encouraging families that have autistic children to submit home video footage of themselves and their children for potential inclusion in Cuarón's film. The press release included extremely detailed instructions (complete with sketched illustrations) about scene composition (for example, all people in the film should be wearing white, autistic people should be filmed alone and then surrounded by family, etc.) (Autism Speaks 2009a).

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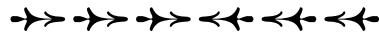
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ASHLEY TAYLOR



# Expressions of “Lives Worth Living” and Their Foreclosure through Philosophical Theorizing on Moral Status and Intellectual Disability

[M]odern man is an animal whose politics places his existence as a living being in question.

—MICHEL FOUCAULT, *History of Sexuality*, VOL. I

The relationship between intelligibility and the human is an urgent one.

—JUDITH BUTLER, “DOING JUSTICE TO SOMEONE”

## *Introduction*



Despite the increasing social visibility of people labeled with intellectual disabilities<sup>1</sup> and the gains made to include them in all the major institutions of society, popular rhetoric, and political discourses continue to call into question the worth of a life lived with intellectual disability. Over the last decade, policy makers, popular media, and diverse advocacy groups have publicly debated about the rights to bodily integrity, reproduction, and self-determination of people with intellectual disabilities, as well as their access to adequate education and their right to live in the community rather than in institutions. In contemporary moral, political, and bioethical philosophy, there has been growing discussion of the relationship between individual humans and their moral status, raising questions that bear significantly on the lives of people with intellectual disabilities. To whom shall the rights and duties of political or civic membership be accorded? Who qualifies as a person in considerations of ethical treatment and care? Who,

or what, is a subject of justice and to whom is justice owed? At the center of these inquiries is the question of the social, moral, and political place of individuals with intellectual disabilities and, in particular, the extent to which individuals so labeled or defined can be said to have moral personhood. These philosophical efforts to clarify the moral status of individuals with intellectual disabilities have, for the most part, been intended to produce more just and equitable social arrangements and ensure individual welfare, although, at times, they respond to concerns over scarce resources.

As public debates continue over what counts as a life worth living, a life of human dignity, and even what constitutes life itself, critical disability studies scholars—especially those working at the intersections of gender, race, sexuality, and disability—have linked this preoccupation to definitions of human life and lives worth living to the prevailing social regard of the disabled body as questionably human, as aberrant, as abhorrent, and as an unfortunate existence (see, for instance, Garland Thomson 1997, 2006; Johnson 2003; Linton 1998; Schweik 2009; Siebers 2009). Rosemarie Garland-Thomson, who describes disabled bodies as representations of “contradiction, ambiguity, and partiality incarnate,” considers “the will to normalize” such bodies as the drive to expunge human differences, to ignore the messiness and non-uniformity of nature, and to control, shape, and regulate all bodies (Garland-Thomson 2006, 262). This well-documented new eugenics of the contemporary world consists in what critical disability scholars have called the “ideology of ability” (Siebers 2009), “compulsory able-bodiedness” (McRuer 2006), or simply “ableism”: the persistent perception—both conscious and unconscious—that disability precludes human well-being and agency and is the quintessential representation of the precariousness of the human condition (Siebers 2009, 5; see also Bogdan and Biklen 1977). Feminist disability theorists and feminist philosophers of disability argue that current ideas about which lives are worth living have real and sometimes deadly material consequences, insofar as they inform policies on (for instance) genetic testing, euthanasia, selective abortion, and rights to bodily integrity, as well as political attitudes toward war and its material repercussions, including loss of life, physical, mental, and emotional disablement, extreme poverty, and more (see Asch 1999; Erevelles 2011; Tremain 2006, 2010; Garland-Thomson 2006; Johnson 2003; Lamp and Cleigh 2011; Shapiro 1993).

The theoretical basis of these arguments is most apparent in the wealth of literature that analyzes disability from a Foucauldian perspective, showing that the social and political forces that individualize and categorize people according to particular social norms effectively produce subjects as

particular kinds of people, kinds that are taken to be natural and have pre-discursive existence (see Allen 2005; Carlson 2010; Tremain 2002, 2005, 2010). Foucault traced the emergence of the disciplinary regimes of medicine and psychiatry, and academic disciplines more generally, demonstrating how bodies and biological life became sites of investigation, regulation, and social control for governmental practices that monitor health, sanitation, and social hygiene, birth rate, and so on (Foucault 1997a, 73). For scholars of disability who draw on Foucault, a Foucauldian analysis therefore offers insight into how disability is constituted as a medical, legal, and academic category whose recognition and expression are the objects of government through state policies and laws—what Foucault calls “biopolitics” (Tremain 2005). In addition, and especially pertinent to my claims in this chapter, a Foucauldian analysis reveals how categories of cognitive disability—such as “idiocy,” “mental retardation,” and “intellectual disability”—emerged and continue to be developed, historically and discursively, thus showing them to have contingent existence (Carlson 2005).

Feminist and other philosophers of disability, many of whom have drawn on Foucauldian methods of analysis, have also waded into the debates about moral status and lives worth living in order to comment on the gendered and racialized assumptions of rationality, independence, and normalcy that uphold dominant philosophical views of personhood (see Carlson 2010; Kittay 2002, 2010; Wong 2010; Stubblefield 2007, 2010). For example, Eva Feder Kittay (2002) describes how liberal definitions of personhood rely on beliefs about normal human ability that are grounded in masculinist ideas about the capacities—including the capacities for rationality and self-sufficiency—and behavior of the white independent adult male (see also Lanoix 2007). To take another example, Anna Stubblefield (2007, 2010) traces the construction of the contemporary western understanding of “intellect” to historical intersections between gender and race ideology and the label of mental retardation, arguing that the concept of cognitive disability cannot be abstracted from the social and political forces that shape the meaning of intellect. In addition to exposing the ways in which deep-seated cultural biases and prejudices against disability steer these public and academic debates, many of the aforementioned authors issue a call to philosophers, bioethicists, and feminist philosophers and theorists to recognize how their own approaches to these fundamental ethical questions can themselves reproduce wrongful and harmful views of disability and the humanity of disabled lives.

I propose that in order to attend to these important insights about philosophical claims about disability and human life and the dehumanizing dis-

course that surrounds people with intellectual disabilities in particular, we should consider a *prior* question in regard to normative theories about the moral status and humanity of people with intellectual disabilities, noting the question's significant import and impact on policy and law. Do these philosophical questions about human life and moral status, politically and practically necessary though they may be, also function to obscure or distort emerging and alternative conceptions of competency, intellect, human behavior, ability, and well-being? Indeed, I maintain that philosophy in general and feminist philosophy in particular would benefit if they were to ask this question *in advance of* other questions about human life and moral status. That is to say, to understand the deep discomfort that people with disabilities,<sup>2</sup> parents of children with disabilities,<sup>3</sup> and advocates and theorists of disability have about normative theories of moral status, we should reframe the question of moral personhood to address the social conditions under which the qualifying conditions for moral status and human belonging arise, in addition to asking what the qualifying conditions for moral status or human belonging are.

In short, I contend that to adequately evaluate the justness of our conclusions about intellectual disability and moral status, we should first interrogate how expressions of human life and personhood are constituted through the analytic practices of our philosophical reasoning about moral status and lives worth living. I maintain, furthermore, that such a project designed to trace the social and discursive conditions under which humanness and personhood are recognized and ascribed would be best accomplished if it were situated within the Foucauldian philosophical tradition, a philosophical tradition that calls into question what has been regarded as normal, natural, and inevitable (Tremain 2001, 2005, 2010). Thus, the analysis that follows in this chapter relies on three important assumptions derived from Foucault's insights. First, Foucauldian genealogy offers us a method with which to recognize and understand the contingency of constructions of bodily difference and categories of disability. Second, Foucault's insight that discursive and disciplinary power operate through academic theoretical and other practices enables us to examine the constitutive power of philosophical reasoning and conclusions. Third, and following from the first and second assumptions, Foucault's challenge to the concreteness of norms and the categories on which they rely suggests the possibility of new ways of understanding the human, moral status, and lives worth living.

Kim Q. Hall (2011) has suggested that the question of a life worth living is not foremost "a question about whether disability impoverishes or

enhances quality of life. Rather the question is, following [Judith] Butler, what makes possible a life that can be lived” (6). In her recent work, Butler has explored what she calls “normative violence” and its relationship to social recognition and physical violence (Butler 2004, 2005, 2009). Butler’s work in this context—and my own work in this chapter—draws on and expands a Foucauldian analysis of power and the operation of norms. As Butler explains it, normative violence makes one intelligible through cultural and social norms of gender, race, sexuality, ability, and so on in ways that render one vulnerable to erasure and exclusion from social, political, and cultural recognition and potentially exposed to physical harm. I aim to consider how debates within contemporary moral and political philosophy that seek to expand the qualifying conditions of human life and moral personhood nevertheless perform a normative violence of their own. Where these approaches measure political recognition and moral status in terms of individuals’ intelligibility through norms, they involve a potentially violent exclusion of possible alternative ways of expressing human life, capability, and well-being. For Butler, social justice requires not the delineation of what counts as human in the service of politics, but rather the creation of the conditions under which moral and political recognition is always fluid and what counts as human is always subject to social contestation. In this chapter, I will argue that Butler’s view of normative violence offers us a way to consider how the identification of moral status, though possibly unavoidable within the scope of political theorizing, is ultimately a *precarious* method for creating the conditions of social justice.

### *Caveats and Clarifications*



First, let me offer a clarification about my goals in this chapter. Although I intend to scrutinize philosophical theorizing about moral personhood and human well-being, my primary focus in the chapter is the discursive and material effects (and *risks*) of such theorizing. I do not wish to dismiss that philosophical work. On the contrary, I recognize that debates about the moral status of individuals with intellectual disabilities are likely necessary in order to defend vital social entitlements and legal protections for the individuals so labeled, especially within a political climate in which their social welfare is often, and dangerously, undervalued. Indeed, where the worth of a life lived with intellectual disability is held suspect, a universal concept of the human is, perhaps, as Tobin Siebers argues, “urgently required, if people with disabilities are to attain the respect due to them and

if we are to make progress as a democratic society” (2009, 93). I shall, therefore, advance the argument that, although it may be pragmatically necessary to appeal to a prediscursive or naturalized notion of the human, to do so enacts particular normative effects. I recognize the urgency of these practicalities, even as I proceed with my caution about the effects of such theorizing about human life and moral status.

Second, in this chapter I consider Butler’s notion of “normative violence” as it applies to intellectual disability and philosophical debates about lives worth living. Some critical disability studies scholars have questioned the application of other aspects of Butler’s claims to disability and disability theory (see Wendell 1996; Siebers 2009; Samuels 2011). For example, Siebers (2009) contends that Butler’s constructivism potentially ignores the physical realities of the lived experience of disability. Others, such as Ellen Samuels (2011), caution against the facile replacement of “gender” with “disability” in appropriations of Butler’s work for feminist philosophy of disability and disability studies more generally. Nevertheless, the promise that Butler’s theories can contribute to transformative theorizing about disability has led to a tendency for critics to at once question and embrace her thinking: “Her insights have the potential to be so far-reaching and liberatory that even as we formulate critiques of her theories, we are also drawn in to the possibilities those theories offer” (Samuels 2011, 63). In what follows, I embrace Butler’s analysis of norms and normative violence as a framework within which to consider how people with intellectual disabilities are excluded from the concept of the human.

*Debating the Moral Personhood of Individuals with  
Intellectual Disabilities*



Debates about the moral status of people with “profound” cognitive disabilities have been the focus of recent work in philosophy of cognitive disability.<sup>4</sup> In their introduction to *Cognitive Disability and Its Challenge to Moral Philosophy*, Licia Carlson and Kittay (2010) succinctly summarize the questions posed in these debates, which include the following:

Are those with cognitive disabilities due the same respect and justice due to those who have no significant cognitive impairments? Are the grounds of our moral obligation different when a human being may lack certain cognitive faculties that are often understood as the basis for moral personhood? Are those with significant cognitive impairment moral per-



sons? . . . *Are the people with cognitive disabilities, especially those labelled as “mentally retarded,” distinct, morally speaking, from nonhuman animals?* (1–2; emphasis added)

How we respond to these questions will have significant consequences for how we subsequently propose that social resources, such as education, health care, and dependency care, should be distributed. Moreover, our responses will determine whether this particular group of people will come to enjoy the same rights and protections (as well as the same duties) as all other people. I emphasize the latter question in the Carlson and Kittay passage quoted above because it involves a comparison between a group of (biologically) human beings and a group of (biologically) nonhuman beings. Some philosophers debate the relevant differences between, on the one hand, individuals with “severe or profound” cognitive disabilities and, on the other, nonhuman animals, suggesting that we need to defend the position that there are relevant differences between the two if we want to uphold a view according to which the former have rights that should not be accorded to latter (see especially Singer 2010; McMahan 2010).<sup>5</sup> Peter Singer (2010, 336) has famously argued that philosophers (and others) who privilege the moral status of individuals with profound cognitive disabilities over the moral status of nonhuman animals with purportedly comparable or more advanced cognitive abilities are guilty of “speciesism,” which he regards as a form of unjustified normative privileging of humans over nonhumans akin to racism or sexism. In response to Singer’s arguments in this regard, Kittay (2010, 405) charges him with epistemic immodesty insofar as he presumes to know, and, in turn, generalizes about, the cognitive capacities of individuals with profound intellectual disabilities. Says Kittay, the people who live and work closely with individuals with these intellectual disabilities acquire intimate knowledge about their capacities, knowledge that directly challenges these presumptions about abilities and capacities. What is salient for my argument in this chapter is that when this question about moral status is posed, the humanity of people with intellectual disabilities is held suspect. As Carlson and Kittay make clear, the view of intellectual disability as “other” denies any recognition that cognitive disability is a feature of the human condition (Carlson and Kittay 2010, 3) and often depends on assumptions about individuals with intellectual disabilities that are wrongful and uninformed (see Carlson 2010; Kittay 2010; Wong 2007; Stubblefield 2010).

Much of the emerging philosophical work on cognitive disability—work that spans bioethics, ethics, legal theory, and moral and political

philosophy—originates in critiques of the centralized place that individual capacities for practical reasoning hold in evaluations of moral status. John Rawls famously outlines a view of the just society in which an individual’s status as a “fully-cooperating member of society” depends on the individual’s ability to exercise certain rights and duties of citizenship, including the capacities to form a sense of justice and a conception of the good over the course of a complete life (Rawls 2001, 18–19; 1993, 18). These capacities—what he calls “the two moral powers”—can be understood as qualifying concepts insofar as they delineate features that individuals must possess in order to be regarded as equal in moral status and as full social and political participants. Importantly, in Rawls’s view, individuals with “permanent disabilities or mental disorders” are not considered to fall within the “range of normal human functioning” when, and because, they do not possess or are not capable of the two moral powers (Rawls 1993, 20). In short, rationality is, in Rawls, as elsewhere in political philosophy, presented as a “chief marker” of moral personhood, a marker of that prized attribute that seems likely to exclude many individuals labeled with intellectual disabilities (Wong 2007, 583).<sup>6</sup>

Within contemporary debates about the political inclusion of and equality for individuals with cognitive disabilities, the Rawlsian view has become an important site of challenge, in particular because of its heavy reliance on rationality as the basis for moral personhood. Martha Nussbaum (2006) has argued, for example, that a different approach is required in order to understand how individuals with cognitive disabilities ought to be included in society. Thus, she defends a framework of justice that considers the conditions under which individuals can exercise capabilities that enable human flourishing. Because in Nussbaum’s view human life is characterized by both rationality and need, moral status is not negated by limitations in rationality (132).<sup>7</sup> Humans are both political and social beings who have material needs, desire to live together with others, and have a deep interest in the ability to make choices about their lives (85–86, 88). We desire a variety of life activities and are born, grow, live, and die in varying degrees of dependency on others, with various impairments and medical needs. Importantly, this approach acknowledges that there are some people among us who live in constant or almost constant states of dependency (167, 87–88). While Nussbaum contends that Rawls’s framework of justice is inadequate to attend fairly and justly to the needs of people with intellectual disabilities, other philosophers have defended his view as ultimately more inclusive (see Cureton 2008; Wong 2007, 2010). For example, Sophia Wong (2010) argues that Rawls should be read as claiming that individuals must

have the *potential* to possess the two moral powers, rather than read as claiming that these powers must be actualized. There is, points out Wong, too much risk of error in determinations of who is capable of rational deliberation and able to communicate their will and who is incapable of rational deliberation and unable to communicate their will; thus, she argues that we should err on the side of inclusion in cases in which we question persons' ability to be full participants in democracy. Given adequate "enabling conditions"—that is, conditions that foster individuals' development of capacities and abilities—individuals with intellectual disabilities can become fully cooperating members of society (143). The promotion of an "idealizing conception of personhood" suggests a view in which all individuals are regarded as potential moral persons (Wong 2007, 594). Wong (2010) writes:

The boundary between moral persons and nonpersons is indistinct and difficult to judge; we should therefore include all human beings without trying to determine exactly where they are on the spectrum of cognitive functioning. The possibility of mistakenly denying someone's personhood is a moral error far more troubling than the difficulty of establishing a society that includes all citizens. (142)

Wong's argument is extremely important because it underscores the fact that our determinations of who possesses qualifying capacities—or even how those capacities will be defined—are currently unreliable and, therefore, we must attempt to be as broadly inclusive as possible in order to avoid potential *wrongful* exclusions. Stubblefield (2010) suggests a similar caution insofar as she argues that "intellect" is a social construction and "cognitive skills are as elusive as skin color and evade measurement as such" (295). Indeed, measurement of intellect is fraught with the entanglement of racialized and gendered norms, and we do not know intellect apart from these discursively constructed qualifications and measurements. Both Wong and Stubblefield point to the elusiveness of accurate determinations of individuals' cognitive abilities, citing as evidence a troubled and damaging history of underestimation, stereotyping, and even outright denial of some individuals' intellectual capacities and communicative abilities (see Wong 2010; Stubblefield 2007, 2010).

Surely it is vitally important to continue the debates surrounding the role and place of individuals with intellectual disabilities in society—as *members* of society. Certainly these discussions are meant to consider who would be discounted in accounts of moral personhood that make reference

to certain capacities and abilities, as well as to ensure that arbitrary and oppressive exclusions are not perpetuated. Perhaps if these discussions were reframed as reconsiderations of fundamental philosophical ideas, new and important insights into justice, equality, and fairness would be produced (Carlson and Kittay 2010, 3; see also Carlson 2010). Nevertheless, I suggest that we must also attend to a deeper question about how these inquiries themselves function to maintain certain ideas about ability and disability. For one thing, these arguments—even the arguments that advocate a reconsideration of philosophical presumptions—*uphold*, rather than dismiss, a sense of stable *qualifying conditions* of personhood and humanity. Arguments about the lines of demarcation seem akin to arguments about “liveable lives,” lives that will be recognized, included, defended. In many of the accounts that attempt to show the discursive formation of norms of intelligence and cognitive ability, we see gestures toward *proving* persons’ capabilities within some newly valued norms, rather than a focus on the conditions that create such demarcations in the first place. So, although we may determine more and more inclusive criteria for personhood and citizenship, we do so at the risk of, and with the knowledge that this involves, enacting determinations of whom to exclude. Where a traditional view of justice usually involves qualifying conditions as the requirement for social and political recognition, an alternative view of justice suggests that it involves looking at the conditions of inclusion and exclusion in a given context and how these always accompany certain formulations of social justice.

### *Constituting “the Human”*



Traditional philosophical conceptions of justice, guided by the imperative to recognize and provide for individuals and groups of individuals, operate according to what Foucault called a “juridical” notion of power (Foucault 1978/1990). Juridical power is best understood as existing in forms of sovereign control, wherein a sovereign individual or sovereign institution of the state (a parliament, for example) represses and controls subjects from above, managing the distribution of resources and relations among them. In this sense, power can be granted or taken away; in other words, power is construed as possessed in the way that a commodity is possessed (Tremain 2005, 4). Foucault contrasted this interpretation of power with his own understanding of power as productive and operating through the actions of individuals within the regulatory and disciplining mechanisms of the state,

such as the prison, the state, and laws and prohibitions that govern sexuality. These disciplining and regulatory mechanisms have positioned individuals as objects of study, dividing the normal from the abnormal, the unhealthy, and the perverse (see Allen 2005). The subject of this “bio-power” is therefore the human and human life itself: “Power would no longer be dealing simply with legal subjects over whom the ultimate dominion was death, but with living beings, and the mastery it would be able to exercise over them would have to be applied at the level of life itself; it was the taking charge of life, more than the threat of death, that gave power its access even to the body” (Foucault 1978/1990, 143).

On this view of power, then, the delineation of qualifying conditions for moral status, or juridical rules that determine who is and who is not recognized as a person, or as a human, is understood to both facilitate and mask forms of power that govern whose life is intelligible and whose life is unintelligible. Indeed, the relationship between what it means to be human, what it means to be granted moral status as a person, and what that moral status confers on someone deemed to be a person is quite literally a vital one. Interestingly, these two concepts—human and person—operate in very different ways within philosophical theorizing, ways that reveal how Foucault’s sense of power—that is, power that operates discursively, through productive norms—is at work. Charles W. Mills (2011) points out that, although the term *human* is commonly used or understood as a straightforward descriptive term (that is, membership in the species human), *person* is a technical, philosophical, and normative term that refers to moral status and is not limited in its ascription to only human, or even organic, life. It is a serious error, says Mills, to assume that one’s factual humanness will entail that one is recognized as normatively human—that is, as a person, with the entitlements and protections that the status of “person” confers. Yet, he says, liberalist theorizing makes this error regularly, conflating fact with normative status and ignoring how “socially recognized personhood” is ascribed independent of biological humanity. Consequently, social convention regulates moral status, rather than some fact about moral personhood, even if some such fact exists.<sup>8</sup> Accordingly, we (currently and historically) know or understand moral status only through discursive norms, norms that govern who is to be regarded as human, whose life is to be valued. How, then, are we to understand this “socially recognized personhood” that is conflated with being human? How, indeed, does such a conflation come about and what possibilities does it obscure?

In “Doing Justice to Someone,” Butler (2001) asks, “Who can I become in such a world where the meanings and limits of the subject are set out in

advance for me?” (621). This question suggests a subject that is intelligible always from within a system of cultural norms, norms that prescribe and frame the subject’s existence and constrain its expression of the markers of personhood, that is, the capacities that individuals are required to possess in order to reach the moral status of person. Central to an understanding of Butler’s notions of agency, responsibility, and ethical relation is an understanding of the subject as emerging from, and constituted within, norms. To be received as a subject is to have one’s humanity recognized, to have one’s humanity acknowledged (Chambers 2007, 46). In *Gender Trouble*, Butler (1999) argues that norms of gender *produce* the body, which is made intelligible only through the prevailing discursive divide between sex and gender. The limits of the subject’s expression, she says, “are always set within the terms of a hegemonic cultural discourse predicated on binary structures that appear as the language of universal rationality” (13). What is understood about the subject—as the subject—is set out within the cultural frames of intelligibility. Butler’s aims in *Gender Trouble* were to show the ways in which our discursive understanding of gender is always inadequate and always incomplete, rendered through norms of intelligibility, as well as to show that “representation is extended only to what can be acknowledged as a subject” (4). That is, there is always a constitutive outside to these demarcations of the subject, exclusions that are at once erased and necessary to uphold what is intelligible. For whenever we demarcate the “normal,” we simultaneously demarcate the “abnormal” (Allen 2005, 94; Tremain 2010). As we shall see, furthermore, this constitutive outside supports the polity and sociality—the inclusive structure—as a specter of what has been normatively rendered unintelligible, unrecognizable, *unaccounted* for.

Butler’s most recent works offer a broader discussion of intelligibility in terms of what counts as human. Moya Lloyd (2007, 137) suggests that Butler’s later work shifts the emphasis from discrete categories of gender marginalization to the broader notion of the human because Butler recognizes that focusing only on already existing categories actually performs its own erasure of others.<sup>9</sup> The shift in emphasis is interesting, I think, as it performs a shift in recognition as well. To focus on the unintelligible intersexed body, for example, as Butler does in “Doing Justice to Someone,” is to focus on what is included and excluded from humanity, what is inaugurated into “humanness,” and what is left outside (Butler 2001, 634). In *Giving an Account of Oneself*, Butler (2005) extends the discussion of the inaugurated subject into the realm of the ethical and ethical responsibility. The “scene of address,” that space in which one is recognized and called forth

into intelligible existence through norms, is fundamentally an exclusionary moment or moment of erasure that marks both survival and (partial) death of the subject. The scene of address, argues Butler, is characterized by judgment, the stance that both presupposes and “establishes a clear moral distance between the one who judges and the one who is judged” (45). This judgment tends toward violence, toward the violent erasure of that which is not normatively intelligible, that which is not known within the cultural frames of personhood or “the human.” Where judgment is taken as social recognition, then, there is a closure of difference, an erasure of possibility of alternative lives and alternative modes of being human. Thus, Butler calls for an “ethical posture” toward the other, a posture that “suspends judgment in order to apprehend the other” (44).

The connection between intelligibility and the notion of “liveable lives”—lives that succeed as/are counted as human lives within a discursive system—becomes very clear in Butler’s *Precarious Life* (2004). In this text, Butler looks at how some lives come to count as grievable in ways that others do not. Once again Butler shows us how our cultural frames orient us toward particular ideas about “the human” (33). What is knowable to us is that which can be understood within such normative frames of the human. Norms of intelligence, competency, independence, and appearance govern how individuals with intellectual disabilities are recognized, not simply as disabled, but as human or *nonhuman*. “Liveable lives” are lives that are included (recognized) within these norms. Non-liveable lives are those that are excluded, foreclosed, rendered invisible. Although these exclusions do not themselves enact physical harm, they create the conditions under which such physical harm can occur: they often enable it, excuse it, and even permit it. Butler calls this form of violence “normative violence,” identifying it as a form of violence that “both *enables* the typical physical violence that we routinely recognize while it simultaneously *erases* such violence from our ordinary view” (Chambers 2007, 44). Where lives are unrecognized, individuals become exposed to physical violence precisely because that physical violence is not, at present, recognized as harm. Their pain, their loss, is un-grievable.

Lest the reader be concerned that Butler’s theorizing about grievable lives is disconnected from the lived realities of people with disabilities in our contemporary world, consider how the un-mourned life is starkly represented in the tragic murders of two young autistic males, one twenty-two years old, the other only four years old, both of whom were killed by their mothers in early 2012.<sup>10</sup> The media response to both George’s and Daniel’s deaths focused overwhelmingly on their respective mothers’ distress about

parenting a disabled child. In George’s case, his mother was portrayed as “a devoted and loving mother,” while George himself was described as “low-functioning and high maintenance” (see Gross 2012). Both George and Daniel were objectified in the public eye as tragic problems, while their mothers were represented as victims of their children’s disabilities. What faded to the background in these media accounts was the tragic loss of the lives of these two young people. Their lives were un-mourned and un-recognized precisely because these lives were framed as less worthy. As one writer for the Autism Self Advocacy Network put it, succinctly, “Because he was autistic, George is being erased from the story of his own murder” (see “Remarks on the Murder of George Hodgins” 2012).

Anne McGuire (2010) offers another important recent example of this relationship between normative violence and corporeal violence in her critical discussion of writer Ian Brown’s narrative about fathering his intellectually disabled son. Brown, she writes, invites a questioning of his son’s very existence insofar as he simultaneously grants value to “disabled life” while enacting cognitive disability as a preclusion of full human life (14). Where we ask what it means to be human, says McGuire,

[t]he non-disabled life is confirmed as the only possible life—a life so full of possibility it can choose how human it wants to be. And, this choice, this act of confirmation is only made possible if the humanness of the “severely” disabled life is understood as uncertain. Conceiving of the “severely disabled” life as “perhaps not human” makes it possible and, seemingly, reasonable for a well respected national newspaper to publish a close-up photograph of the face of a cognitively disabled child, next to the large bold print question: “Am I human?” (14)

Through such narratives, wherein readers are invited to assess what it means to be human in light of cognitive disability, normative judgments become the arbiters of the intelligibility of others and the possibility for liveable—human—lives. The jump to judgment means that “we lose the chance to be ethically educated or ‘addressed’ by a consideration of who [these others] are or what their personhood says about the range of human possibility that exists, even to prepare ourselves for or against such possibilities” (Butler 2005, 45). For Butler, acting ethically cannot be reduced to making moral judgments; to do so is to close off possibilities for experiencing others differently. The moral judgment, like its legal counterpart, establishes this moral distance between judge and judged, something that directly counters the sort of ethical relation that *enables* existence or differ-



ent possibilities for personhood and social intelligibility. The ethical posture therefore demands “suspending judgment,” as I noted above, for by “not pursuing satisfaction and by letting the question remain open, even enduring, we let the other live, since life might be understood as precisely that which exceeds any account we may try to give it” (43).

Before I proceed to discussing the ways in which the contemporary debates about moral personhood can be re-thought in light of Butler’s notion of the ethical posture, we must come to understand exactly what grounds our ethical relation to others, what propels such a response of “letting be” or “letting live.” What, indeed, accounts for this suspension of judgment when cultural and discursive forces would seem to propel us toward judgment? For Butler, the ethical posture arises out of a recognition of our mutual—that is, our collective—vulnerability to norms: we are intelligible, coherent subjects in virtue of, and on the basis of, the contingent norms that we ourselves constitute and perpetuate. Yet, insofar as we are subjected to and constituted by and through norms that are *contingent*, we are always on the brink of unintelligibility, of being rendered non-subjects in the shifting discourse of what counts as the normative human. We are, says Butler, physically dependent and physically vulnerable to one another (Butler 2004, 27). To understand this relation of vulnerability, though, is not simply to understand relationality and interdependence as they have been discussed in much feminist literature. Rather, this relationality expresses a much more vital concern, one that governs the very *possibility* of our existence in relation to other subjects who act through and perpetuate normative systems (27). Vulnerability is not (only) a lived condition but a condition of living. The ethical posture consists, then, in the recognition of our vulnerability to norms and the normative system.

### *The Risk of Normative Theories of Justice*



I have explicated Butler’s ideas about how to re-think the human as constituted through and by norms, rather than as a being that has a prediscursive existence, ideas expressed in Foucault’s philosophy that subsequently have been taken up within philosophy of disability and disability studies (see, for example, Allen 2005; Tremain 2001, 2002, 2010). Philosophers and other scholars of disability hold that Foucault’s exploration of biopower reveals how the medical and statistical sciences produce impairment through the comparison of the body that is judged as healthy and able-bodied with the body that is judged as unhealthy and disabled, thus producing, according to

Shelley Tremain, the illusion of impairment as having a prediscursive— or natural—existence (Tremain 2005, 11; see also Tremain 2001, 2002). Insofar as norms are products of the disciplines used to measure them, however, they have “no physical being or reality apart from that practice” (Allen 2005, 94). These disciplinary practices in fact govern how bodies appear and which bodies are legitimated as belonging to the human community, itself a discursive construct. What it means to be human, and certainly what it means to be recognized and valued as human, is constituted through these discursive practices of biomedical analysis and measurement.

These ideas are not uncontroversial. To suggest that determinations of who, or what, counts as human are discursively produced is to dispute that there exists a sense of human that can be found out or qualified definitively.<sup>11</sup> According to this view, our notions of what counts as human are, therefore, not closer and closer approximations of the truth of what it is to be human and what features humans as political creatures (or otherwise) possess, but rather are normative expressions of liveable or intelligible lives. To focus, therefore, on the creation of a concrete normative theory to address injustice and inequality is to *risk performing* the sorts of exclusions that social justice aims to eliminate. The notion of equality itself seems to involve an “ideal of impossible inclusiveness: who is included among those who might make the claim to equality? What kinds of issues undermine the very possibility of certain groups making such a claim?” (Butler, Laclau, and Laddaga 1997, 5). What possibilities for *life* have we closed off when we imagine inclusion? Butler writes that “there is no polity, no sociality, no field of the political without certain kinds of exclusions having already been made—constitutive exclusions that produce a constitutive outside to any idea of inclusiveness” (5). Democracy’s task, it would seem, is not to abide a normative theory of justice, but rather “to keep open any given universalization of content” (10). This openness acknowledges the risk of normative erasure and potentially enables the recognition of new forms of human expression.

I have argued that philosophers need to confront the “risk” involved in normative theorizing about justice and moral status, even as they acknowledge the simultaneous necessity of doing such theorizing. Yet it seems an impossible task. How can one confront the realities and practicalities of moral questions and legal policies and— simultaneously—suspend moral judgments, that is, avoid drawing conclusions? Indeed, Nussbaum (1999) finds this latter suggestion infuriating. She claims that Butler is “adamantly opposed” to normative notions of human dignity, something that Nussbaum attributes to Butler’s argument according to which we should take up

what emerges in the political struggle, rather than form a normative theory in advance. Nussbaum contends, however, that addressing social injustice involves “discussing which liberties and opportunities human beings ought to have, and what it is for social institutions to treat human beings as ends rather than as means—in short, a normative theory of social justice and human dignity” (42). Thus, Nussbaum regards Butler’s resistance to “a normative theory of social justice” as evidence of her “moral passivity” (42), her failure to distinguish between resistance that is conservative and resistance that is subversive.

I take the disagreement between Nussbaum and Butler to concern what modes of social justice work look like. For Nussbaum, the movement toward justice consists in a prescribed normative theory, one that clearly articulates and distinguishes between norms that count as good and norms that count as bad (43). Butler’s approach to social justice work is, however, quite different from this approach, that is, quite different from Nussbaum’s view. For one thing, Butler regards norms as neither bad nor good but rather as always both potentially liberating and potentially oppressive. Furthermore, although Butler sees concrete coalition work, political struggle, and legal judgment as necessary (see Butler 2005, 45), she situates her understanding and view of social justice elsewhere: not in a normative *theory*, but rather in normative *contestation*. To hold fast to a normative theory of justice is to ignore, neglect, or overlook a whole range of alternative norms that enable and constrain who will count within that theory. Justice is “not only or exclusively a matter of how persons are treated, how societies are constituted, but also emerges in the quite consequential decision about what a person is, what social norms must be honored and expressed for personhood to become allocated” (Butler 2001, 622). For Butler, social justice demands an ongoing critique that extends even to such important normative theories as Nussbaum’s.

I think it is easy to see why a scholar who is as concerned with social justice as formulated within normative theories of inclusion and equality as Nussbaum is would find Butler’s contentions frustrating. Butler seems to be, as Jodi Dean (2005) worries, avoiding politics, avoiding condemnation of the bad and praise of the good. Whereas Nussbaum accuses Butler of a “naïvely empty politics,” though, Dean regards Butler’s approach as “a politics of avoidance.” The trouble, for Dean, is that Butler does not give us the tools that we need to deal with people who would reject her ethics, who would reject her interpretation of social justice (64). Dean’s critique of Butler is certainly more friendly than Nussbaum’s, but it nevertheless points to a challenge in our reception of Butler’s politics. The challenge consists in our desire

for a politics that expresses or points to clear *action*, action that can be called transformative and ameliorative. I am not sure we can find such direction for action so clearly in Butler. Rather, Butler's sense of politics reminds us that our actions are, to recall Foucault, always dangerous, always potentially liberating, and potentially oppressive (Foucault 1997b, 256). This position should not lead to apathy, however, but to what Foucault calls a "hyper- and pessimistic activism" (256). What Butler's politics does for us, then, is suggest a way in which to challenge normative theories, acknowledging that regardless of how practically necessary they may be to us, they always involve conditions that exclude. We can recognize that the human "comes into being, again and again, as that which we have yet to know" (Butler 2004, 49).

*Humanity, Vulnerability, and the Contestation of  
Moral Personhood*



How, then, might we helpfully and productively perform this sort of challenge to normative theories that describe what justice looks like for people with intellectual disabilities? Are philosophers wrong to seek to establish clear normative grounds for inclusion and equality on the basis of moral status? To help us answer this question, let us consider the following story of social exclusion from Wong (2007). A professor and his class gather for a field trip that involves travel on a bus, which is supposed to be equipped with a wheelchair lift so that the one student who uses a wheelchair will be able to accompany his classmates on the bus. When the bus arrives, however, the driver says that its lift is broken and that the student who uses a wheelchair must wait for the next bus to come. The other students in the class leave for the trip on the first bus, while the one student who uses a wheelchair remains behind and actually misses most of the trip because the second bus arrives late. For Wong, this illustrates a certain insensitivity on the part of the students, an insensitivity that betrays a lack of the civic virtue of solidarity that would require them to remain with their peer and wait for the second bus. We might say, in fact, that these students call into question the moral status or equality of their peer insofar as they leave him behind. Wong argues that it is not enough to look to the law to create just institutions and just social arrangements; rather, we need to cultivate the civic virtue of solidarity with people with disabilities (583). In short, Wong prescribes a mode of social engagement and possibly protest that would change individuals' orientation toward disability and inclusion.

This seems to be an important moment of political contestation, and I

am certain that Butler would applaud such moments of solidarity. Nevertheless, there are two important ways in which this sort of political resistance is *precarious* as a means of achieving social justice. First and briefly, Butler cautions that the same norms that find meaning in the law also take shape in our individual beliefs and individual modes of relating to one another (see 1999, 20). That is, such civic virtues of solidarity could also lead to a normalizing and excluding politics when, for example, particular cultural values find residence in socially promoted virtues, values such as unity and sameness, which can undermine expressions of difference. Second, the resistance to a political structure upholds, rather than troubles, the normative conditions under which determinations of exclusion—of who counts as incapable of voting, for instance—are made; it challenges the manifestation of the exclusion, not the exclusionary *process* itself. Thus, in addition to contesting qualifying conditions—the conditions that suggest inclusion or exclusion—we need to contest the normative or discursive conditions of those decisions, decisions that delineate belonging and recognition. This process of contestation demands not (only) the possession of civic virtues, but also the recognition of our mutual vulnerability as subjects in norms. To contest the very normative or discursive conditions of qualifying conditions is, therefore, to contest the conditions of our own potential erasure. In a discussion of this ethical posture, Joris Vlieghe (2010) writes:

[W]hereas traditional philosophy is obsessed with the problem of legitimating our moral obligations towards others and the community by grounding them in a kind of positive essence of what it means to be human or belong to a community, Butler argues that it is precisely the negative experience of the radical lack of any such ground that guarantees moral and communal bindings. (158)

This juxtaposition of the traditionalist philosophical approach and debates about moral status with the Butlerian view of our moral and political connections as grounded in radical vulnerability and normative dependence expresses exactly the way in which our view of moral personhood ought to shift to reflect new grounds of moral obligation and responsibility. It is important, though, to be reminded that this dependence on others, that is, this vulnerability to others, does not have to be understood as subordination (Oliver 2000, 40). Rather, Vlieghe (2010) suggests that it is precisely in our communal sense of being “beside ourselves,” of seeing the vulnerable other in us, of witnessing our own potential normative erasure, that we can know ourselves to be equal to others (161). This, then, is the “equalizing

experience” of vulnerability. To grant someone the status of human being “is not so much a matter of giving them permission as just letting them be as human” (Siebers 2009, 93).

I would argue that grounding a view of moral personhood in this equalizing experience of vulnerability moves us to an entirely new and important understanding of “the human,” one that rests not on qualifying conditions or thresholds of ability, but rather on the responsibility that we have to each other as normatively vulnerable beings. I contend that feminist philosophers and philosophers of disability could stand to learn from this ethical posture in their efforts to imagine a more just view of social obligations to people with intellectual disabilities. I am not, however, arguing that we must abandon debates surrounding moral status and moral personhood, but rather that we approach them with an eye to understanding how our theorizing performs a normative violence of its own precisely through the closure and finitude involved in the delineation of qualifying conditions of “the human” or “person.” Certainly we must acknowledge the practical *necessity* of making ethical decisions, defending moral attitudes, or indeed acting in the service of politics. If we view these as tentative, even precarious, social justice efforts, however, we may come to acknowledge that the concept of the human is “a work in progress” (Siebers 2009, 92).

#### NOTES

1. I refer to people “labeled with intellectual disabilities” in order to call attention to this category or classification “intellectual disability” as a disputed construction (see Carlson 2010; Linton 1998; and Rapley 2004). I will, henceforth, refer to “people with intellectual disabilities,” but encourage readers to keep this theoretical orientation in mind.

2. See, for example, Gross 2012; Docherty et al. 2010; Kennedy 1994.

3. See Bérubé 2010; Kittay 2002, 2010.

4. *Cognitive disability* is a term used by many philosophers. For the purposes of this chapter, I use *intellectual disability* and *cognitive disability* interchangeably.

5. Kittay and Carlson’s (2010) edited volume *Cognitive Disability and Its Challenge to Moral Philosophy* contains a number of chapters that describe and continue this debate.

6. There is some disagreement about whether this consequence of Rawls’s theory is necessarily harmful to or problematic for people with cognitive disabilities (see Wong 2007, 2010; Cureton 2008).

7. However, Nussbaum does suggest that some individuals may be said to lack “a characteristic human form of life” (2006, 181).

8. It is important to note that for Mills whether one has the moral status of a per-

son is ultimately an objective or, in poststructuralist terms, a pre-discursive fact; that is, it is not a product of social convention (see Mills 2011, fn. ii). This, as we will see, differs considerably from Butler's view. The question of whether moral status is an objective fact or a discursive formation (or something else) is the subject of much philosophical debate that I cannot explore here. See also note 11 below.

9. See Samuels 2011 for further discussion of Butler's work as applied to disability.

10. It is also, I would argue, clearly represented in the much-discussed case of the so-called Ashley Treatment (see Hall 2011; Lamp and Cleigh 2011).

11. This position differs significantly from the position of those who contend that moral status is ultimately objective and not a product of social convention or discourse. For more on this debate regarding the subject in feminism, see the exchange between Butler and Seyla Benhabib in Benhabib et al. 1995. See also Webster 2000.

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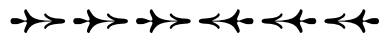
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KATEŘINA KOLÁŘOVÁ



Death by Choice,  
Life by Privilege

*Biopolitical Circuits of Vitality and  
Debility in the Times of Empire*

Given the number of films released during the year of 2012 (or thereabouts) that explore old age and waning capacities, we might be inclined to refer to that year—though not without a certain measure of hyperbole—as “The Year of Spectacular Debility.”<sup>1</sup> My loose adaptation of Robert McRuer’s (2006, 13–15) evocative phrase—“The Year of the Spectacular Heterosexual”—foregrounds this chapter’s inquiry into both the contemporary circulation of images and narratives of incapacitation and the fantasies of sovereignty that are invoked as solutions to such scenarios of incapacity, disability, and debility. The acuteness with which the contemporary cultural imagination engages with the themes of old age, death, and debility—in the latter of which theme a primary role is delegated to so-called degenerative diseases and disabilities—demonstrates that the current historical moment is a period of anxious recognition for the global North with respect to its own *biological precarity*, the term that we might use to refer to this novel and intense form of vulnerability and collapse of illusions of biological sovereignty, both individual and collective. Biological precarity seems to motivate cultural narratives that offer affective release and affirmation as they conjure scripts (that is, fantasies) of solutions and resolutions of these biological failings of the global North. In this chapter, I draw upon Foucault’s ideas about (among other things) the biopolitical, neoliberalism, and the autonomous (neoliberal) subject to explore visions of the resolution of biological precarity, the affective appeal of these visions, and their functional deployment within and by larger ideological structures of transnational capitalism. My analysis in the chapter begins with a brief synopsis of the narratives of two films—John Madden’s *The Best Exotic Mari-*

*gold Hotel* and Michael Haneke's *Amour*—which should serve as an apt preface to the chapter's discussion of the mutually constitutive relations between biological precarity and debility in the times of Empire.

Madden's *The Best Exotic Marigold Hotel* is, as one reviewer put it, the story of “transplanted Britons [who] shake off the North Atlantic chill on a life-altering trip to warmer climes.” As the reviewer seems to recognize, this story itself is not novel; thus, he adds, “Instead of Italy in the 1920s, the place of renewal is Jaipur, India, and the time is now” (Holden 2012). This reference to a long tradition of Brits/northerners who seek rejuvenation in the South is in fact important, although the reviewer refers to it only to cast it off as a mere innovation in the continuation of a long-established tradition. The review implicitly (even if unintentionally) makes visible the legacy of orientalism and coloniality, despite the fact that the reviewer does not directly reference the history of British colonial exploitation of India. His reference to the present moment (“the time is now”) puts into relief the fact that the current political economy and multifaceted experience of precarity, which have emerged due to “changes in the compact between capital and the state” that mark the historical present, might, in a variety of ways, condition the adventurous journey of the British pensioners (Berlant 2011a, 2).<sup>2</sup> Suffice it to say (for now at least) that the designation of Jaipur and India as the “place of renewal” identifies them as places where the characters are provided with what they need to sustain themselves and even flourish, that is, to get what they could not get in their home country. Hence, “place of renewal” is a euphemistic phrase, calling up orientalist fantasies of paradisiacal locations of plenitude and referencing neo- and post-colonial practices of reproduction of (white) life. As I discuss in greater detail later in this chapter, “place of renewal” is a location where life for the northern debilitated and precarious subjects is (still) sustainable and economically feasible, albeit at the cost of the exploited labor of others (racialized and disprivileged subjects) and reliance on structures of globalized capitalism. Interestingly, too, this euphemistic phrase conceals the fact that the “transplantation” and “outsourcing” (to use the language of the review) of oneself into a foreign land—the big adventure of the film's narrative—describe a “choice” enforced on many through the workings of neoliberal capitalism and its destruction of social networks and securities. Thus, the phrase “place of renewal” is shorthand for the marriage between white supremacist fantasies of privileged lives and the structures of political economies that simultaneously make possible and even profitable the increased precariousness of some lives and sustain the transnational distribution of life and vitality.

Haneke's *Amour*, arguably the more critically acclaimed film of the two, in the telling of a story of current biological precarity in the global North, provides a different angle on, and, apparently, a different script or solution to, the crisis of debility. *Amour* depicts an elderly heterosexual couple, both retired Paris-based bourgeois musicians. As the husband and wife age, she has a stroke, which begins her descent into the debility that the film frames and dramatizes. In a reversal of the conventional gendered script of care, the husband is assigned the role of compassionate, loving, and gentle carer. The gradual decline of both the wife's and the husband's capacities becomes the focus (indeed, the *sole* focus) both of the narrative and of the visual representation. In keeping with his fame and notoriety, Haneke provides a dramatic closure to this spectacular chronicle of debility. For at the end of the film the husband, ostensibly guided by compassionate awareness of his wife's suffering and fierce love of independence and life (previously expressed as a preference not to live dependent on the care of others), sings his favorite childhood rhymes to her and then chokes her to death. The husband, having performed what is widely regarded as the ultimate sacrificial act of love, subsequently leaves their conjugal home and sets off to confront (what viewers are led to believe is) his own death. This narrative strategy lures the audience into reading the act of killing as an act of mercy and, perhaps, an act of last rites. Indeed, as reviews of the film indicate, this luring technique delivers on its promise. With admiration, reviewers have described the film as "a moving story of love and loss" (Hornaday 2012) that seems to encapsulate "human experience," that is, to put us "in touch with essential elements of humanity such as love, sacrifice, and mortality" (Berardinelli 2012).

Both the ending of Haneke's *Amour* and the sentimental politics that the film deploys to construe—and, legitimize—the act of killing as an act of love are worthy of critical discussion. The film's narrative has incredible power to persuade the film's audience (and reviewers) to accept the script of romantic (heterosexual) love as both a "genuine step toward humanism" (Hornaday 2012) and a "profound statement about what constitutes true love" (Berardinelli 2012), covering over the deeply controversial resolution of the narrative. Furthermore, the heterosexual romance, with its unconventional gendering, which apparently emphasizes the avant-garde nature of the entire story, is utilized to awaken and uphold the phantasm of the sovereign subject. Notice, however, that the "sovereignty" in question is not achieved merely, or predominantly, in relation to one's life, but rather performed with respect to determination of the conditions of one's *death*.

The success of Haneke's *Amour*, which has won the Palme d'Or, the

Academy Award for Best Foreign Language Film, and multiple other professional accolades, enables me to propose that the film’s narrative achieves an affective release to current preoccupations with biological precarity and the waning capacities of northern populations. Furthermore, I want to argue that the narrative’s unconventional and deliberately shocking closure is offered as a solution to impeding debility under the shifting conditions of “the social.” In this way, *Amour* dramatizes how the debilitated body becomes the location on which social, as well as biological, precarity can be (magically and spectacularly) resolved through performances of (illusory) sovereignty performed in control over the biological body.

Due to its comedic tone, *The Best Exotic Marigold Hotel* did not strike its audience as a film with high stakes in the redefinition of the contours of liberal subjectivity, as *Amour* did. Its matter-of-fact reproduction of ideological structures of orientalism and its engagement in legitimizing biopolitics is, nonetheless, of crucial import to precisely these reconfigurations of the subject. Thus, despite the differences in the respective narratives, *Marigold Hotel* and *Amour* (and the other cultural texts that I discuss over the course of this chapter) raise questions about how fantasies of sovereignty and promises of autonomy, choice, and freedom essentially corroborate ideologies of (racialized, classed, and ableist) difference and dominance.

This chapter constitutes an inquiry into the ways in which biological precarity—as currently construed in relation to debility in the global North—motivates and revitalizes ideologies of Empire and white supremacy. Drawing on and elaborating Jasbir Puar’s use of the term *debility*, I offer “debility” as a conceptual paradigm through which to interrogate the ways in which neoliberal capitalism extracts vital capacities from certain individual and collective bodies in order to “revitalize” others and, furthermore, ask how the notion of debility can be used to motivate inquiries into the ways in which incapacities and even death are rescued for global/transnational capitalism. In order to motivate this inquiry, I shall first revisit the debates around end-of-life decision making and assisted dying. I shall in turn contextualize these debates within the broader geopolitical context of Empire (Hardt and Negri 2000).

### *Biopolitics of Disability and Debility*



Elizabeth Bouvia’s pleas for voluntary death in the second half of the 1980s may well have initiated the public controversy that quickly became per-

ceived as the “agonizing debate” over “assisted dying” (Gibbs 1990).<sup>3</sup> When, a quarter of a century later, that is, in 2006, Anne Taylor, a British physician who had previously been diagnosed with neural degenerative disease, claimed her right to access “assisted dying,” she (like an increasing number of Europeans) died in exile at the Swiss clinic Dignitas, which provided her with the means to commit physician-assisted suicide. In her plaidoyer for legalizing “assisted death,” Taylor invoked a collage of neo-liberal humanist principles—humanity, dignity in death, individual freedom, autonomy, and choice—that have, over the last decade especially, gained increasing jurisdiction over end-of-life decisions made in a number of European countries and some states of the United States.

These shifts in legislation of matters of death (and life) attest to more than a liberalization of social norms and prescriptions. The current discussions indicate very clearly that assisted dying is now conceptualized as a matter of general democratization and the liberalization of society and, more pointedly, a matter of citizenship rights. For example, in newspaper coverage of her case, Taylor repeatedly invoked her agency to speak *as a citizen* when she stated that “to die with dignity should be everybody’s right” (quoted in Savill 2006). Notice that Taylor’s claims to a “right” to die with dignity went well beyond the usual critique of the state’s invasion into the lives of its citizens. For she also charged that the state had failed to perform one of its primary functions, namely, the protection of its citizens’ lives, in addition to effectively inflicting harm on them. The British state, Taylor is quoted in this newspaper article to have said, forced her into premature death by compelling her to enlist the services of Dignitas while she was still able to travel abroad, albeit perhaps not ready to die. As she put it, “Our law is shortening rather than prolonging life” (*ibid.*).<sup>4</sup> Indeed, access to “voluntary death” and “end-of-life solutions” has become more and more frequently deemed the new threshold to a humane and liberal society. Jerry Dincin, the vice president of the American organization Final Exit, has named the “right to die” *the* “human right of the 21st century” (quoted in Bowers 2009)! Thus, we might ask, what does this concurrence of the arrival of the “right to die,” on the one hand, and the demise of the “right to health” (Greco 2004),<sup>5</sup> on the other, tell us about biopolitical government of life, vital capacities, and debility? How should we understand the fact that while the campaign for the “right to die” continues to gain support and popularity, doing so under the banner of the fulfilment of democratic ideals and a more noble ethics of life, “the notion of a ‘right to health’ appears . . . more controversial and problematic than ever, as the sustainability of welfare states is increasingly and explicitly in question” (1)?

Paul Longmore's (2003) careful commentary on Bouvia's case situates her wish for death against the lack of social provision and family and community support for disabled people and, thus, calls for a structural analysis of disability's place in the circuits of capitalism, disrupting the taken-for-granted and allegedly intuitive assumption that Bouvia's disability is the reason for her death wish. As Longmore's analysis of the assisted suicide foreground, the fact that Bouvia's case coincides with the onset of the neoliberal politics of privatization, individualization, and market therapy (see, for example, Harvey 2005; Klein 2007; Rose 1996) must be underscored.

The emphatic embrace of "the right to die" at the brink of the financial crisis that brought harsh austerity measures and increased precarity—measures that disproportionately impact disabled people—should compel reflection (Goodley, Lawthom, and Runswick-Cole 2014; McRuer 2013; Wood 2011; Wood 2012; Wood and Grant 2010a, 2011; Wood, Cheetham, and Gregory 2011). What gets lost, and what ethical conflicts are falsely resolved, through euphemistic terms such as *assisted dying* and *end-of-life decisions*? What does it mean that, although the "human right of the 21st century" is not articulated in terms of "the right to health care" or "the right of access, welfare, and solidary social provision," "the right to die" is regarded as such a momentous human right? And indeed, what are the ramifications of the discourse of "the right to die" as a defining line of citizenship in times of biological precarity and under the neoliberal restructurings that, due to privatization, favor the upward redistribution of resources ("the incredible shrinking public," as Lisa Duggan [2003] famously dubbed it)? This chapter addresses these (and other) questions related to the intensified demands for health, capacity, and life that mark neoliberal forms of citizenship in order to contribute to, and enliven, conversations between the fields of Foucault-inspired studies of biopower and governmentality, on the one hand, and disability studies on the other. Although both fields of inquiry have engaged in exciting analyses of the neoliberal present, they do not always profit from mutual critical exchange. The discussion in this chapter aims, therefore, to increase the possibilities for such exchanges.

I maintain that this historical moment of biological precarity reflects shifts in the discourses of citizenship and in the relationship between the state and governance of life/death, as well as in the means through which both life and death can be turned into forms of capital. These dynamics enable us to ask new questions in relation to biopolitics and, in particular, to the forms of biopolitical investments of disability and ability. It is, nevertheless, a conspicuous paradox that the bulk of literature that interrogates "the politics of life itself" (Rose 2007) does so while ignoring disability as



one of the categories vital to the very nature of power that the theory sets forth to analyze. In the editor's introduction to the first edition of this collection, Shelley Tremain lays out very clearly that disability—both as an abstract category of thought and as the phenomenon that has given rise to a type of individual—was prompted into existence through biopolitical practices of objectification, subjection of otherness, and classification of “human kinds” (Tremain 2005, 3–5), all of which practices have constituted norms around which and in respect to which the biopower of modernity distributes its subjects. Thus, insofar as the literature on biopower ignores the ways in which disability shapes both the *techné* and the *ethos* of neoliberal biopolitics, the critical analyses produced therein themselves contribute to the dynamics of neoliberal governance.

Foucault's insights into the mechanics of power that shape modern liberal and late liberal (or neoliberal) societies, as well as his general suspicion of “the liberal citizen as a package of freedom” (Bell 1996, 83), promise to further critical reflection on “assisted suicide” insofar as these insights critique the discourses of right and choice, as well as the (simplified) notions of autonomy that dominate public discussion of these issues. Foucault rejects and meticulously deconstructs the generally accepted repressive hypothesis that posits the modern subject as a subject who needs to be rescued by progress in order to achieve freedom. For Foucault views freedom (and the visions thereof) as an effect and function of normalizing mechanisms, regulatory strategies, and technologies of power; that is, these mechanisms, strategies, and technologies produce the very subject of freedom. The pervasiveness of power in modern societies, for which Foucault (1991, 2008) coined the term *governmentality*, lies in modern power's ability to “produc[e] people with certain kinds of subjectivities [and to constitute] subjects whose actions are governed through the exercise of their own capacity to choose” (Tremain 2006, 50). With his concept of governmentality, Foucault abandons the vision of the sovereign state as “a coherent apparatus of juridical power” and proposes to “address the multiple ways in which social relations are ordered and controlled through a network of institutional and personally directed regulation” (Shildrick 2009, 62). Thus, as Margrit Shildrick sums it up, all demands for new freedoms and choices must be “inherently ambivalent,” insofar as they “inevitably invite new forms of governmentality” (62).

To advance these analytical and critical ends, Foucault (2008) offers the concept of *homo oeconomicus* as a modality of (neo)liberal subjectivity, a modality through which, he argues, the principle of individual choice provides nothing more than “well-regulated and ‘responsibilised’ liberty”

(Barry, Osborne, and Rose 1996, 8). In other words, the promises of choice and freedom are turned into a way of assigning responsibility for agency within strictly regulated range of choices. In what follows, I therefore propose to consider the promise of autonomy that has been injected into the “choice equals the right-to-die” equation as a form of affective politics conjured in the face of precarity and, more specifically, as a form of affective politics that might in fact foreclose what it allegedly guarantees.<sup>6</sup>

Disability must be one of the analytical perspectives through which we chart the formation of the subject under the conditions of the flexibilized nature of (neo)liberal normalization. Indeed, this chapter speaks to the dearth of disability-informed perspectives within governmentality studies by outlining the ways in which disabled subjects become appropriated and utilized in the service of government. Shildrick’s *Dangerous Discourses* (2009) illustrates the subtle ways in which neoliberal governmentality operates on and through disabled people. Anne Waldschmidt’s (2005) analysis of prenatal testing and screening reveals that disability becomes the field on which the neoliberal dictum of choice and autonomy is (compulsorily) exercised. Tremain (2006), too, addresses the ways in which the discourses about disability that surround prenatal testing and screening employ the autonomous liberal subject. In various ways, these texts lay the groundwork for my own inquiry into the discourses of autonomy and choice in relation to assisted dying and neoliberal governance. Neoliberal governance is in fact characterized, as Antke Engel’s concept of “projective integration” indicates, by “pluralis[ing] the norm [that] provid[es] positive images of difference” (2007, 127; also see Engel 2009; for discussion of projective integration to disability, see Kolářová 2011). Thus, we must ask not only how promises of choice are deployed as vehicles of governance, but also, and as importantly, what ideological labor the disabled subject performs in the legitimization of these (disciplining and regulative) “choices” in order to make them intelligible and even desirable in this particular historical moment of austerity, biological precarity, and transnational “outsourcing” of the frail.

### *Subjugating “Freedom of Choice”*



The British organization Dignity in Dying has been at the forefront of campaigns to change U.K. legislation that governs “end-of-life” decision making. The organization’s website publicizes statements of its patrons (many of whom are public and influential figures) who speak out for the

legalization of assisted and “voluntary” deaths, providing an informative insight into discursive framing of the justification of assisted suicide. Here are some examples:

“We live in a *free society* with all the *choices* that go with it. We *choose* when to marry, have children, what treatment we should have, . . . in fact how we should live our lives. This should include the opportunity to choose the time we die.” (Emphasis added)

“Just as *we have civic and legal rights*, so it is not for the state and the medical profession only to decide how we should die. We should be able to participate . . . [in] the right to a *good death*.” (Emphasis added)<sup>7</sup>

These statements foreground the key terms and assumptions that underpin almost all the public discussions of “assisted dying.” The implications of these terms and assumptions can be summed up in the following way. The notion of the (individual) right to die is defined as the moment of an individual’s emancipation from the state and its institutions so that he or she is able to exercise acts of choice. Furthermore, the ability to perform such a choice is framed as *the* marker of a “free society.” However, statements such as “we choose when to marry,” “we choose to have children,” and “we choose what treatment to undergo” caution us to reconsider the understanding of choice as something that automatically extricates us from restrictions and regulative power; in fact, statements such as these uncover the fallacy of understanding the illusory choice as equal to a “right,” as equal to unlimited freedom. To be sure, we are allowed, perhaps even encouraged, to “choose” to marry, to “choose” to have children. To what extent, though, may we “choose” to marry a disabled partner? To what extent may we “choose” to have disabled children, let alone wish for them? The paradoxical nature of choice consists precisely in the fact that “choice” passes as an expression of subjective autonomy and simultaneously functions as a normative requirement. As Nikolas Rose notes, “[T]he modern self *is institutionally required* to construct a life through the exercise of choice from among alternatives” (1990, 231; emphasis added). The choices that the individual makes become the means with which to construe a culturally recognizable life; that is, “individuals are expected to construe the course of their life as the outcome of such choices,” yet the register of choices is contingent on normative frameworks and material conditions. Each choice is, thus, “an emblem of our identity, a mark of our individuality,” and the articulation of an “account for . . . the reasons for those choices” (231) Choosing has become the *performative* act that construes our

lives, our selves. Consider the performative character of this remark on the Dignity in Dying website. “I think it’s time we learned to be as good at dying as we are at living,” Terry Prachett, the famous writer, states. The imperative to *become* as good at dying as we are at living suggests that dying—similar to acts of living—must be turned into a result of careful choices, management, practice, and the art of (self-)care. Prachett’s statement *summons* “us” to a new ethical project of lifelong learning and preparation in which death is no longer the antonym of life, in which the “art” of dying *must become a part of* the art of living. What do the accounts of the choice to die (and its rationale) tell us about both the formation of the subject and the contingencies of such choices? And what does it mean when we define a “good death” in terms of choice—that is, “choice” that the hegemonic order of compulsory able-bodiedness posits in definitional conflict to disability?

Almost concurrently with Taylor’s public defense of her choice to die, another case involving assisted suicide caused a public stir: the case of a twenty-four-year-old professional rugby player, Daniel James who, after he became paraplegic due to a sports injury to his spinal cord, opted for early death. In 2008 *The Times* solicited the following op-ed from John Harris, an acclaimed British bioethicist. This expert in (bio)ethics offered these remarks.

I think it is perfectly intelligible that somebody would prefer death . . . to [a] continued existence almost totally paralysed. We can understand why that would be a rational choice to make. . . . There have been many cases of competent people fearing a particular unpleasant sort of continued existence, wanting to arrange their death in circumstances that they would find more tolerable than allowing death to come upon them willy-nilly. (Harris 2008)

I leave aside the most blatant stereotypes and the abjection of disability expressed in off-hand references to “continued existence almost totally paralysed” that allow the ethicist (!) to presume that “we [all] can understand” that the wish to die is “a rational choice to make” in the face of “continued existence almost totally paralysed.” As Harris’s remarks show, he evidently considers James’s choice of death a choice that ought to receive moral endorsement. It is striking and worth our attention that Harris provides his high evaluation of “[this] rational choice” in very specific—and expressly normative—terms: the choice of death is intelligible, an expression of rational management, and an expression of competency and resistance to the “willy-nilly” upturn of biology. In brief, Harris’s statement brings back

into play the Cartesian fantasy of the sovereign subject who exercises full control over *his* embodiment and articulates a specific economic rationale of a “good death.” Harris defends the young “paralysed” man’s decision to die as a decision of someone who is “the entrepreneur of himself, [someone who is] for himself his own capital, . . . his own producer, [and] the source of [his own] earnings” (Foucault 2008, 226). The decision is valued and given moral support because it is, as Harris argues, economic in the sense of “rational conduct . . . sensitive to modifications in . . . the environment” (269). In other words, the ethics that the famous bioethicist proposes is the *ethos* of *homo oeconomicus*.

Together Prachett’s and Harris’s assertions encompass what, with Foucault, we could call the *ethos* of the choice to die. Both statements require that death be transformed from the messy and arbitrary collapse of biology into an event, an act, and a practice of citizenship. As the “good death” becomes the emblem of the “good life,”<sup>8</sup> one’s self-determined choice over the conditions and forms of one’s death is envisioned as the ultimate sign of an owned life and an ideological threshold that distinguishes socially recognized, valued, and intelligible forms of life.<sup>9</sup> Despite the prevalent conviction that the push for “good death” breaks new ethical ground and is a marker of democratization and liberalization of (post-)modernity, Stefanie Graefe’s (2007) genealogical study of “end-of-life” decisions renders evident that the demand for the “right to (choose to) die” was preceded by the demand for a “natural death.” This legacy is still discernible in the endorsements that defend that “right” as a means of emancipation from the influence of medicine. Importantly, Graefe notes, the access or right to a “natural death” has historically overlapped with social distinctions and class. As death became more expansively medicalized, privatized, and individualized (also in the sense of a marker of individual identity), the vision of “natural death” was turned into a marker of social privilege (81).

In short, the distinction between, on the one hand, the well-managed good death that is a result of the rational evaluation of one’s life and, on the other hand, the death that simply happens (“willy-nilly”)—a distinction that, as we have seen, Harris assumes in *The Times* op-ed, and one that is generally embraced in arguments about the notion of choice in death—has a distinct historical legacy. Recognition of this legacy should motivate us to expand the scope of critical engagement with “assisted dying,” that is, expand its scope beyond both its current breadth and the realization that phantasms of the subject who “actively shap[es] his or her life course through acts of choice” (Foucault 1991) are, in fact, effects of power that operate to make the rationally acting *homo oeconomicus* into “someone man-

ageable, . . . eminently governable, and subject to subjection” (Foucault 2008, 270; see also Rose 1996, 50–62). An expanded critical engagement with (so-called) assisted dying should include discussions concerned with social hierarchies and the fact that life itself is distributed through privilege and unequal principles of legitimacy (Fassin 2009). As Graefe’s work highlights, the “dispositive of natural death” (Graefe 2007, 83) reflects ideologies of “natural” social stratification and hierarchy instrumentalized in the construction of the collective bourgeois identity, as well as biopolitical classification and disciplinatio through norms (82, 74–85). It is indeed immensely important that this particular historical legacy of the discourses of “right to die” be revealed insofar as it uncovers the links between the discourses that normatively qualify moments of death/vitality cessation with broader ideological and economical contexts (such as the rise of capitalism and the rise of an ideology of normalcy, coupled with a categorization of disability) that are invoked in articulations of what is valuable and what is worthless in/as a life.

To sum up the above discussion, the politicization of notions of a “good death” or a “natural death” indicates that death can no longer be conceived as outside of power. Rather, as Judith Butler notes, “[I]n the maintenance of death and of the dying, power is still at work and that death is and has its own discursive industry” (Butler 1995, quoted in Graefe 2007, 84). As counter-intuitive as it might seem, death incites the management procedures characteristic of the modern power that, according to Foucault (1990), rationalizes care that is concerned with “growth,” “reinforcement,” and “availability” of life and its capacities, driven to bring “life and its mechanisms into the realm of explicit calculations” (141, 143) in order to make the most frugal use of life and its generative potential. “[I]t is the power to *make* something live or let it die, the power to regularize life, the authority to *force* living not just to happen but to endure and appear in particular ways” (Berlant 2011b, 97; emphasis in the original).

As I have indicated, the binary opposition of life and death is, at least at present, false. The project of “growth,” “reinforcement,” and “availability” of vitality and life’s capacities is built on the legacy of exploitation and extortion of vital forces. In the economizing terms of biopolitical logic, life and death are actually interconnected poles. (Not) letting die is a form of biopolitical regulation of life and economic rationalizations of vitality.

What insights can we derive about the forms of power in which we currently live once we have recognized that the choice of death is now made intelligible through the logic of self-entrepreneurship and economic rationality? And what can we learn about biopolitical conditions of the repro-

duction of life and capacity under the conditions of transnational capitalism by analyzing “the ever-shifting ‘foldings’ into and out of life and death” (Puar 2012, 164; see also Puar 2011)? The juxtaposition of debates around the management of death and debility with practices of reproduction of (privileged) life at the end of this essay is designed to start these important and overdue conversations.

### *Biological Citizenship: Death as a Citizen’s Right?*



Insofar as I appreciate the ramifications of the discursive move to define death (and the choice to die) as a rubric of citizenship, I propose, with Rose, to explore what “ethical demands [such a discursive move makes] possible on oneself, one’s kin, one’s community, and one’s society, as well as the people who exercise authority [over oneself and others]” (Rose 2007, 133). The cases of Bouvia, Taylor, and James (and we could name many more) alert us to ways in which the assisted suicides/deaths of some people are figured as means of emancipation and freedom for other people, indicating that the notion of “everybody’s right” is dangerously close to becoming transfigured into someone’s *responsibility*. With this dynamic in mind, I want to argue that we need to shift the conversations around assisted dying and the so-called end-of-life arrangements from assertions about notions of choice, rights, and autonomy to (and here I echo Puar’s call) “questions of bodily capacity, debility, disability, precarity, and populations” (Puar 2011, 149, 152), as well as introduce new questions that will attend to ways in which in/capacities are utilized for capitalization. In the rest of this chapter, I consider the role of disability and the circuits of capacity/debility, as well as what this relation tells us about the new figurations of biopolitics and biopolitical capitalizations on life/death in the face of biological precarity.

The definition of the choice of death as a “civil right” marks the ongoing shifts in the ways in which the status of citizenship is defined, and illustrates the ultimate biopoliticization of life (and death) that Rose and Carlos Novas (Rose and Novas 2005) describe as “biological citizenship” (see also Rose 2007). That the status of citizenship has become defined through the ability to determine one’s own death, rather than defined through other biological and biopolitical dimensions of life and vitality (although these dimensions likely would be no less complicated), raises new questions that demand to be considered. The concept of biological citizenship has been extremely useful and insightful for conceptualizing the ways in which “life itself” is

invoked in struggles for forms of political agency and redress claimed in relation to injury, illness, and/or conditions of survival (see Rose 2007, 134). For instance, Adriana Petryna's groundbreaking study of post-Chernobyl Ukraine's formation of citizenship shows how "a large and largely impoverished segment of the population has learned to negotiate the terms of its economic and social inclusion using the very constituent matter of life" (Petryna 2002, 5). Yet, now we see redress claimed not in relation to survival and the possibility of life, but rather in relation to specific practices of death.

In another context, Shildrick (2009), in her careful appraisal of the push for sexual citizenship for disabled people, claims that the acceptance of normalizing disciplinary constraints always accompanies the success of these emancipatory claims. It is possible to develop her cautionary note beyond the scope of normalization that goes hand-in-hand with recognition of citizenship. As the debates around assisted suicide reveal, the proclaimed emancipation that access to assisted suicide is said to afford effectively depoliticizes rhetorics. The discourse of right and choice deflects attention from a focus on power and its mechanisms as it individualizes and privatizes notions of autonomy and choice, as well as other biopolitical issues. Of course, the discursive framing of the "right to death" efficiently deflects attention from more urgent issues, including issues of (access to) health care and survival. The illusory promise of recognition and freedom attached to the discourse of the "right to choose" in this case may thus have life-destructive and potentially fatal effects for many other people than simply those who are now campaigning for this new element of autonomous and liberalized citizenship. The immediacy of such inquiry becomes more evident when we ponder the burdens attached to the allegedly emancipatory agency of these definitions of biological citizenship. Shildrick elaborates this point when she writes, "[The] push for that status [of sexual citizenship] seems to be more about gaining legal and social rights for a sexual *identity* than for the protection of specifically non-normative sexual *behaviours*" (2009, 75; emphasis in the original). Shildrick's remark is of essential importance for my current discussion insofar as it foregrounds the normalizing effects of citizenship and emphasizes that the discourse of emancipation does not necessarily open space of more (and more variant) options of *ways* of living/dying in/with debility, but rather sets out a new paradigm of normative models of life and death. As Rose (2007) puts it, biological citizenship construes links between "biology and human worth" and defines "[clear and] new distinctions between good and bad subjects of ethical choice and biological susceptibility" (132, 134). It would be difficult



to miss echoes of Rose’s observation in Harris’s evaluation of the “rational choice” that James—the “totally paralyzed” young man—made, in the public acknowledgment of Taylor’s bravery in her fight to travel to Dignitas, and even in the awards and accolades given to *Amour* for its unflinching depiction of humanity and love’s hard labors.

*On the Deathbed: Re-capacitating the Debilitated*

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The current discourse that surrounds “assisted deaths” attests to shifts in definitions of the status of citizen/ship and its relation to the biological. The Dignity in Dying website provides apt examples of these changes. My aim is to explore how the arguments made on the site, arguments that frame the right to die as a civil right, deploy in/capacity and dis/ability.

Nobody asks to be born. *Life is thrust upon us*. Who are you to try and force me to stay if I’m suffering at the end of my life? (Emphasis added)

*We have no control over how we arrive in the world*, but at the end of a life we should have legal control over how we leave it. (Emphasis added)<sup>10</sup>

These two statements indicate that the discourse of the “right to death” calls forth notions of sovereignty defined in terms of a release from one’s own biology, in addition to emancipation from the state. That is, the act of death is envisioned as an act of (re-)claiming control over one’s life/biology. In this way, the statements unmask the paradox written into the forms of biological citizenship articulated around “voluntary dying.” In the context of voluntary death, that is, both normative ethics of competence (death should not come upon us “willy-nilly”) and governance over the precarious and biological that is susceptible to illness, disability, and incapacity condition claims to emancipation. In other words, life itself becomes the seat of the claims that deconstruct the state’s power/sovereignty over subjects and must be simultaneously relinquished in order for these claims to be fully proven and achieved. The sovereignty of the self—and its supposed freedom from external rule—thence comes to its fullest expression in the act of death.

Disability and in/capacity are at the heart of these fantasies of sovereignty. The choice of death is always argued through, and in relation to, life with disability/debility, as choosing to die becomes the exercise and practice of self-affirming agency in the face of encroaching incapacity. To

exemplify, let me point out that Taylor is, through media and press representation and, in particular, the BBC-produced *A Short Stay in Switzerland* (2009), transfigured as the incarnation of *homo oeconomicus* par excellence. *A Short Stay in Switzerland*, a feature film based on Taylor's life, fashions her "descent" into debility as a preview of her eventual overcoming and triumph over debility in the act of asserting of her will/right to die. In her initial attempts to explain her choice to her (at first) disapproving family and friends, she compared her situation to that of her recently deceased husband, who also suffered from a "debilitating" condition and whose increasing "debility" and utter dependence on the help of others is emphasized (beyond endurance) by the visual representational strategy of the film. Taylor's husband thus serves as the foil underscoring her own rational "self-ownership." Taylor knows what is awaiting her, calculates her remaining capacities, and puts them to use in asserting her "choice." She is portrayed as someone whose decision and *choice* are governed by an "economic" logic that allocates scarce resources to particular ends, that is, as someone who manages through careful and rational handling to transform "*chance to choice*" (Bröckling, Krasmann, and Lemke 2004, 232; translation and emphasis mine) and, in doing so, achieves a sovereign position over biology.

This positing of Taylor as the model of entrepreneurial subjectivity bespeaks additional ways in which disability plays a central role in the (neoliberal) discourse of "choice of death" and, perhaps, even to neoliberal governance more generally. Nevertheless, the real attraction of Taylor's character lies in her ability to transform a bad chance (of debility) into a good choice (of death). Taylor legitimizes the rational and economically founded logic of a "dignified death," while she also embodies (the illusion of) the transgressive avant-garde of future freedom in death choices. For *A Short Stay in Switzerland*, as well as Taylor's other public portrayals, dwell on the fact that her decision contravenes both the law and conventional ethics. As paradoxical as it may sound, given that these discussions and representations are about debility and dying, they are in fact offered as a *futural* gesture, insofar as they represent Taylor as a subject who, in the midst of her own tragedy, breaks ground for future changes. The transgressive positionality is indeed what spins the interpellative mechanism of "projective integration." Such a positionality thus fulfills a "double function: the majoritarian subjects can project their desires onto the images of difference while the minoritarian subjects enjoy inhabiting an avant-garde position" (Engel 2007, 127). In other words, the appreciation directed at Taylor (construed as the exemplary disabled/debilitated subject) for her unusual and

emancipated decision is an instrument of governmentality that works in two interlocked ways: while the disabled subject is offered as a trendsetter and an ultimate pioneer of future-oriented and visionary emancipation into freedom and heightened respect for (individual) life, the same positioning allows for new (and newly legitimized) avenues of abjection of disability.<sup>11</sup> Simply put, the disabled subject is offered the promise of recognition (and integration) only when it becomes an exemplar for the dominant ideology, which, ultimately, devalues disability, debility, and modes of existence that are not recognized through the normative notions of valued *life*.

We might, in fact, say that it is this contingent and mutually constitutive function as both a rational subject of biological sovereignty and a subject of transgressive futurity that “re-capacitates” the previously debilitated Taylor into an exemplar of the responsible and rationally behaving citizen and, as I argue below, “re-capacitates” her for the purposes of neoliberal capital. The previously disvalued and “debilitated” body is given new values in the act of self-destruction, which upholds the ideology of individual freedom so deeply useful to neoliberal/capitalist governance. Thus, the previously debilitated body becomes re-capacitated (that is, given new capacities) both for its ideological labor and for its role in political economies that still remain to be charted.

The disabled/debilitated body, caught in the ideological process in which it is folded back into the economy of vitality through re-capacitation (in death), exposes what Monica Greco (2000) describes as the “vacuous” nature of subjectivities that governance of the late liberal democracies produces and shapes. Her coinage of the term *homo vacuus* expands Foucauldian deconstruction of liberal concepts of freedom and autonomy. In Greco’s vision, *homo vacuus* is *homo oeconomicus*’s shock of recognition, which exposes the falseness of the promise of freedom. After strenuous self-discipline in accordance with the imperative to rationally economize, articulate, and follow the transgressive code of conduct necessary to achieve the promise of individual freedom and agency under which the neoliberal subject of *homo oeconomicus* operates, it can be recognized that there is no inner core to the neoliberal subject that allegedly needed to be freed. The subject is indeed vacuous, devoid of any “inner” self. This, then, is the paradox of neoliberal subjectivity: the neoliberal forms of governmental power accommodate critiques of themselves and turn them into their own strength, whereas neoliberal government even utilizes, for its own purposes, the refusal to conform to conventional social rules (see Graefe 2007; Greco 2000; Tremain 2005; Shildrick 2009).

My discussion in this chapter has attempted to unmask as an illusion the

freedom that is promised through the ostensible “right”/“choice” (of death), which in fact invites and fosters subjection to governmentality. I have foregrounded the political (and ethical) ramifications of this subjecting promise and falsely emancipatory *ethos* of the notion of the “good death.” One of my aims in this chapter has been to indicate how “promises” of this sort actually depoliticize the larger landscape of shifting definitions of the public and the private, as well as depoliticize the identification and acknowledgment of state responsibilities toward the health and welfare of its citizens. I have also suggested that the debates that have ensued around these issues are indicative of shifts in the definitions of biological citizenship and, in addition, may be (and very probably are) instrumentalized more so in shifting the social into the arena of privatized, individualized responsibilities. With the acute attention paid to political economies of health at present, we must be concerned with the conspicuous juxtaposition of debates that, on the one hand, give centrality to individual rights and autonomy in death as opposed to, on the other hand, arguments of individualized responsibilities in health. The newest analyses of the most recent austerity politics document in a depressingly clear manner that “austerity kills” (Stuckler and Basu 2013; see also Blyth 2013). Thus, I have proposed to refocus the debates around death from notions of individual rights and choices toward modalities of biological citizenship and management of vitality, as well as toward explorations of the ways in which debility and disability become instrumentalized for the neoliberal management and economy of lives and, as I shall elaborate at the close of this chapter, within the circuits of transnational capitalism.

When the category of disability is articulated as a flexible relationship between capacity and debility, additional, and more theoretically, politically, and ethically capacious, questions can be asked. For instance, the question “How does the rhetoric of assisted dying impact disabled people?” can (following Puar) be expanded and reframed thusly: “Which bodies are made to pay for ‘progress’ [and visions of futurity]? Which debilitated bodies can be reinvigorated for neoliberalism, and which cannot?” (Puar 2011, 153). Or “How are the debilitated bodies invigorated for neoliberalism and with what ramifications?” In this historical moment, it is essential to engage in questioning that explores the significance of the ideological process of re-capacitation in the ways in which debilitated bodies are posed as exemplary models of sovereignty in acts of self-destruction (a.k.a. voluntary dying) within the context of transnational and global Empire. Recent studies have provided insights into (neoliberal) practices through which the vitality of the global South is drained and exploited in the service of the

reproduction of life and capacities in the global North (see, for example, Vora 2012; Erevelles 2011; Rajan 2006) and how biotechnology creates relations of neo-imperialism (see, for example, Cooper 2008). These neo-liberal practices also radically challenge the theoretical and political landscape of disability studies.

To provide one concrete example of the global exploitative circuits of vitality, in the autumn of 2012, the German public finally took notice of an entrepreneurial solution to the care crisis that has been flourishing in Germany and Switzerland for several years,<sup>12</sup> namely, the “outsourcing” of elderly and disabled people (in particular people with Alzheimer’s disease) to Thailand and other countries of the global South. Even a brief glance at the advertising materials of these care homes and centers reveals the racialized and gendered dynamic that sells them.<sup>13</sup> The challenge for future disability discussion is obvious: how are structures of disablement complicated through transnational circuits of care that are founded on racialized privilege and white supremacy? Clearly, the structural disadvantage and ideological devaluation that previously defined and conditioned the lives of disabled northern subjects are crucially redefined and definitionally complicated insofar as structural, racial, and class privilege is conferred on them in care arrangements wherein subjects of the South are turned into exploitable sources of reproductive labor.

In order to close my discussion in this chapter, I shall consider again *The Best Exotic Marigold Hotel*, one of the film narratives that marks what, at the outset of the chapter, I called “The Year of Spectacular Debility.” Arguably, the melodramatic and grave narrative of *Amour* does not have much in common with the light tone and humor of *The Best Exotic Marigold Hotel*. Furthermore, the solutions that the two films offer to the realized precarity of life and debility differ dramatically; with respect to the latter film, the phantasm of resolution is achieved—as I briefly explain—through life enabled by white privilege and (neo-)colonial access. Nonetheless, we need to consider the ways in which the discourses of “death by choice” enable and serve forms of “life by privilege,” as well as the ways in which all these discourses serve fantasies of sovereignty, marking the complicated circuits of vitality/debility in the times of Empire.

Let us return, then, to the narrative of *The Best Exotic Marigold Hotel*, and its protagonists, as it was introduced in the previously quoted review.

Its seven travelers are financially distressed men and women of retirement age lured by an invitation to “outsource” themselves for a stay at the newly opened *Best Exotic Marigold Hotel* in Jaipur. Upon arrival,

they discover a place that is far from the luxurious retreat “for the elderly and beautiful” that its advertising claims. But after much grumbling, most of them take it in stride and begin to flourish. (Holden 2012)

This lengthy quote from a *New York Times* review of the film draws out what is pertinent for my discussion in this context, chronicling how precarity experienced in the global North reproduces forms of exploitative (neo-) colonialism and elicits racialized notions of privileged lives. To clarify, the protagonists’ decision to leave England should not be misunderstood as the decision to embark on a sought-out adventure to lighten the years of a dull, if comfortable, pension. Rather, for most of the protagonists, the resolution to “transplant themselves” (as reviews have referred to their move) to India is painful and forced on them as a direct consequence of the most recent crisis of capitalism and the collapse of financial markets: houses and life savings were swallowed in bad investments, joint replacements and health care have become inaccessible, and, in general, as one review notes laconically, “[T]he local [Indian] prices make the retirement possible for them” (Ebert 2012). The structures of racialized Empire and the legacy of orientalism make it possible for *The Best Exotic Marigold Hotel* to conjure a fantasy about the resilience of the “elderly and beautiful” (Holden 2012) characters who resemble—as the reference to “we” and “us” in one of the reviews suggests—the subjects of the global North and who, “through [their]/our ability to overcome [their]/our fears, reconcile [their]/our pasts, and start [their]/our lives anew, no matter how old [they]/we are,” enjoy new possibilities and life opportunities at “the twilight” of their/our lives (Kim 2012). In short, *The Best Exotic Marigold Hotel* combines the figuration of *homo oeconomicus* with the never really outdated visions of the Orient to invoke an illusion of an instant solution to both social and biological precarity. Indeed, the narrative construction of the two juxtaposed global locations calls on the ideological structures of orientalism, and these structures do not go unnoticed, as we see in the reviews. The “northern chill,” “financial distress,” and “outsourcing” that characterize the crisis-stricken global North are contrasted with visions of Jaipur, India, as the proverbial paradise, a “place of renewal” and rejuvenation, a place where the life of the northern subject “begin[s] to flourish” again, a place where it is “reproduced.” Insofar as the narrative of the film focuses on the phantasmatic figure of the sovereign subject, the film utilizes fantasies of the Orient and simultaneously detaches itself from their ideological import in the hurtful history of colonialism. The biopolitical significance of the narrative of (self-)re-capacitation through “the right to death” lies beyond the scope of

individual lives, for it is part of the strategies of multiplication of life that uphold and reinvigorate the structures of global dominance. Hence, it is vital that we ask how the fantasy of biological sovereignty of the (northern) subjects contributes to racial privilege and fantasies of Empire. Such questions become acutely pressing as we witness an explosion of the ways in which the global South is exploited for the reproduction of life and capacities of the global North.

In other words, the “choice” of death needs to be considered against a larger and broader context of the politics of vitality and the exploitative economy of capacities. The biopolitical perspective thence necessarily shifts the present debates around death choices to questions about the relationship between the “freedom to die” and current globalized forms of the capitalization of life, capacities of life, vitality, and even death. Furthermore, cultural texts such as *The Best Exotic Marigold Hotel* remind us of Hardt and Negri’s argument (2000) about Empire’s biopolitical nature and, thus, demand that we ask about the relationship between the “death by choice” (that is, death that is promoted as an emerging field of personal autonomy and freedom) and the forms of enforced exploitation of life that Lauren Berlant (2011b) calls “slow death”: the prolonged draining and wearing of vital capacities invested in the drawn struggle for survival and maintenance of life. In particular, the “slow death” of populations in the global South (though not only in the global South) must be part of our discussions of “assisted dying” precisely because the drawn-out labor of survival is the flip side of the reproductive labor that supports privileged lives. In order to open up such a conversation, therefore, I have offered an interpretation of the “emancipated death” debates in juxtaposition to practices that, through the apparatus of white privilege, invest certain lives in the circuits of transnational care.

Both examples of the “solution” to biological precarity that I have discussed in this chapter are results of structural conditions that use and reproduce phantasmic visions of choice, sovereignty, and individual agency, as well as particular visions of the sovereign white subject. The link to racial discourses is perhaps more apparent in the orientalizing imagery of the global South and in racialized practices of neocolonialism that uphold and reproduce the “natural life/vitality” of the subjects of the global North; nevertheless, race and whiteness also play important roles in discussions of assisted dying. The concept of “natural death” belongs to the historical lineage of colonialism and discourses of race (Graefe 2007, 86); it is important to bear in mind that practices that use the capacity of the global South to foster the life of the global North find strange allies in the fantasies of

northern sovereignty performed through the rational and “economizing” choice of death that buttress the ideology of supremacy. Even if these practices and discourses appear to be radically different—one confirming life through (outsourced) forms of care and the other arguing for death as the ultimate assertion of one’s owned life—they are in fact intertwined through their ideological and structural backgrounds. Furthermore, as I have aimed to show, neoliberalism conditions these “choices,” part of the ideological labor of which is to boost and support neoliberalism’s grip through visions of racialized sovereignty.

#### NOTES

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1. The term was introduced into disability analysis by Julia Livingston (2005, 2006). Jasbir Puar (2009, 2011) has expanded on Livingston’s concept in ways that are instrumental for my own argument.

2. The concept of precarity has drawn so much attention because it also offers transformative horizon. For instance, Lauren Berlant invokes precarity as “an ideological term, a rallying cry for a thriving new world of interdependency and care that’s just not private” (quoted in Puar 2012, 166). Similarly, Judith Butler views precarity as a critical gesture toward self-transformative politics that recognizes and acknowledges forms of dependency, vulnerability, and conditions of suffering but would also be “a radical act of interpretation in the face of unwilled subjugation” (2009, 61). My present discussion of bio-precarity and deconstruction of the phantasmic resolutions is motivated by this horizon.

3. The issue of “assisted suicide” or “end-of-life” decisions has been widely discussed across disabled communities and disability studies fields. It is beyond the scope of this essay to provide an adequate overview and proper credit to all participating authors and/or community, artist, and activist platforms. Suffice it to say that arguments foregrounding choice of death as a manifestation of individual preference and freedom have been largely rejected within the disability studies fields with a view to structures of disablism and ideologies of compulsory able-bodiedness and able-mindedness that effectively preclude the assumed “free choice.” The very promise of free choice of death is viewed as a mechanism of oppression (Morris 1991; Gill 1998; Garland-Thomson 2004; Asch 2006; see also Dolmage and DeGenaro 2005a,b). Yet the issue is far from unanimously agreed upon. Some disability scholars attempt to



define grounds on which to re-consider “assisted suicide” with regard to choice for people with disabilities. For example, Tom Shakespeare (2006) argues that “assisted suicide” should be perceived as a matter of autonomy for disabled people too. Nonetheless, his conceptualizations of autonomy do not, and cannot, account for structural or ideological abjection of disability. Margrit Shildrick’s (2008) challenge to the debate’s insistence and oversimplification of both life and death lays the ground for further bio-political reevaluations of “assisted suicide.”

4. This stance is repeated by other proponents of legislative change. Citing the case of Anne Taylor, the following statement is attributed to the chief executive of the UK-based Dignity in Dying, Deborah Annetts: “The government must make time in parliament for the assisted dying for the terminally ill bill. Only this bill could have prevented Anne Taylor from taking her life early. . . . [S]he would be alive today” (quoted in Boseley and Dyer 2006).

5. “Right to health” is not an established phrase in the civil rights vocabulary. Monica Greco uses it loosely to refer to welfare systems and social provisions that are directed at health care. She explains, “The phrase, in other words, tends to be used only as a shorthand for other expressions such as the right to health care, the right to health protection, or the right to healthy conditions, taken singly or in combination. This reflects, and where relevant it formalizes, the notion that health per se cannot be guaranteed—only specific services and conditions can” (2004, 1).

6. Here I am drawing on Lauren Berlant’s thesis of “cruel optimism” (2011b) and Sara Ahmed’s deconstruction of the wish for happiness (2010).

7. All quotes are taken from the website of Dignity of Dying, a prominent British organization engaged in lobbying for the change in legislations related to death choices. Originally named Voluntary Euthanasia Society it changed its name to Dignity in Dying. Your Life, Your Choice, marking the changes in the discursive footings of the debate and showing how the rhetoric of choice and owned life gains ideological power. All the statements used in this text are pronouncement of the so-called ‘patrons’ of the campaign and were publicized at the organisation’s website. <http://www.dignityindying.org.uk/>

8. My argument does not rely only on these statements. A steadily growing amount of counseling literature and online resources give practical guidance about the ways in which to compose living wills, formulate end-of-life decisions, and articulate so-called compassion protocols and other forms. For an illustration of the general note of these materials, see, for instance, *A Better Way of Dying* (Fitzpatrick and Fitzpatrick 2010).

9. As Butler notes in her essay “Sexual Inversions,” death “must always be the death, the end of a specific way of life; and the life to be safeguarded is always already a normatively construed *way* of life, not life and death pure and simple” (Butler 1992, 348; emphasis in the original, quoted in Graefe 2007, 84).

10. Pain, suffering, and other affects are frequently invoked in the debates; however, their role in creating an “affective public” is beyond the scope of this chapter. For a discussion of the uses of (chronic) pain and suffering in relation to disability and assisted suicide, see the work of Alyson Patsavas (2012).

11. It is, of course, horribly cruel that the disabled subject is here figured as the

model of citizenship through and in the act of self-destruction and death. The complexity of this paradoxical positioning of the disabled subject becomes fully apparent when its role (its appropriation) in the debates around assisted dying and “end-of-life choices” is juxtaposed with the practices of prenatal testing and screening that aim to control and minimize the birth of disabled children. Further, the symbolic recapitulation of the disabled subject as the model citizen is where it is important to reframe disability critiques of what Rosemarie Garland-Thomson calls the “cultural logic of euthanasia” (2004).

12. The German public debate over this transnational outsourcing of care for elderly and disabled people happened only a few years after the legalization of the “Self-Determination of Patients Bill”—the so-called *Patientenverfügung* legislation—which is equivalent to the “living will” legislation in North American contexts. The *Patientenverfügung* legislation was passed in 2004.

13. See, for instance, information provided on the websites of these care-centers Baan Kamlangchay, <http://www.alzheimerthailand.com/AlzheimerThailand/Index.htm>; or Ban Farang <http://www.altenpflege-thailand.de/>. I discuss the practices of the transnational care surrogacy in my book project provisionally titled *Post-socialism, Post-coloniality: Global Politics of Racialization and Disablement*.

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