



## Madness as disability

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### Abstract

How does society imagine mental illness? Does this shift radically over time and with different social attitudes as well as scientific discoveries about the origins and meanings of mental illness? What happens when we begin to think about mental illness as madness, as a malleable concept constantly shifting its meaning? We thus look at the meanings associated with ‘general paralysis of the insane’ in the nineteenth century and autism today in regard to disability. In this case study we examine the claims by scholars such as the anthropologist Emily Martin and the psychiatrist Kay Jamison as to the relationship between mental illness, disability and creativity. Today, the health sciences have become concerned with mental illness as a form of disability. How does this change the meaning of madness for practitioners and patients?

### Keywords

Autism, bipolar disease, disability, madness

With interest in mental illness from the standpoint of the growing field of disability studies comes a problem for the medical humanities (Callard et al., 2012; Longmore and Umansky, 2001). Is it possible to discuss what may well be the most stigmatizing form of illness or disability in the West without understanding the complexity of the tradition in which it stands? The diagnostic history of mental illness is entangled with the history of madness as a social convention, a history that colours even the contemporary debates about the meanings and forms of mental illness in our age of brain imagery and neuro-anatomy. These historical images shape the world of the medical professional as well as that of the layperson. We all carry conflicting and competing images of what mental illness means and how it is to be affectively as well as intellectually understood. Such images impact on the meanings associated with the science of mental illness as well as the reception and self-perception of those who are disabled because of mental illness. There is no fine line between images from the world of the health sciences dealing with mental illness and health and these popular images (Quayson, 2007). These images are interchangeable, each reifying the other. Mental illness is real because it fulfils our expectations of the image of madness; mental health is the alternative to such images. This is not to claim that mental health and mental illness do not exist. Only that they are so categorized because of how we imagine madness. Indeed, the interpretability,

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flexibility and malleability of the symptoms of mental illness (as with all symptoms of illness) over time reflect the expectations built on the interplay of popular and medical images.

It is evident that to attempt to capture the relationship between madness and disability is to define one ambiguous and constantly shifting term by another. Madness has for centuries had legal and medical meanings; those meanings are more tangled and subject to political/ideological pressures than ever today in light of the framing of madness as a type of disability. For madness has now not only to figure itself in relation to ideas about competency, moral ability, curability, etc., but also in relation to questions of access, stigma and advocacy (Pelka, 2012). Madness thus evokes not only the wide range of stereotypes of psychological difference (from the Greeks to the present), but also the lived experience of those who understand themselves and are understood as being mad. The term suggests the medical, social and cultural categories dealing with all forms of psychic pain that came under the purview of alienists, psychiatrists and neurologists. By contrast, madness can also be understood from a patient/client/inmate perspective rather than that of a psychiatric practitioner or clinician's perspective.

What seems to define madness in relationship to disability is the concept of psychic pain (or anguish or suffering). The very existence of psychic pain, for example, is today thought to be a contested source of knowledge, having its modern origins in John Locke's view that '... Pain [is] ... sometimes occasioned by disorder in the Body, sometimes by Thoughts of the Mind' (Locke, 1690, Book 2, ch. 20: 113). However else madness has been defined, such psychic pain was and remains a litmus test for madness, whether as a reason for intervention or as a perceived source for greater insight into the mad and their creative capacities.

A broad understanding of madness therefore must account for medical perspectives (both allopathic and complementary/alternative practices) as well as multiple social, political and cultural understandings of madness and mad people, all fluid and ever moving across the world. Every society has its own categories and perspectives and experiences of madness — from melancholia in ancient Athens to spirit madness in modern Evangelical churches; from the representations of madness of American medical missionaries in China in the nineteenth century to those selling cures for madness in the botanicas of the Dominicans in New York City today. Across the globe, societies see categories of madness as something that impinges on human activity, for ill or for good, and with a variety of meanings that generate a variety of interpretations. The realities of what constitutes madness in any given society or community or historical moment are constantly shifting: symptoms change and their meanings seem always in flux. Even as different aetiologies and meanings of madness emerge to explain the somatic, psychological, social and cultural causes of madness, psychic pain remains central to all of these categories. Madness may be the antithesis of what is called normal. Likewise, it may be related to other categories of illness and pain, or be a state that transcends the normal (Gilman, 1982; Porter, 2003).

Similarly, if we explore madness not in the realm of a medicalized society but in the parallel world of the law, then madness takes on yet other colorations. The two realms are intertwined. From the forensic definitions of madness created by the Romans, which focused on competency, aging and property, to the McNaughton rule of Victorian England, which focused on the moral ability to know right from wrong in the case of Daniel McNaughton, who attempted to assassinate the British Prime Minister Robert Peel in 1843, we see legal definitions of madness that parallel and mimic medical and social definitions of madness. But these legal definitions are also autonomous. Today, one does not speak of madness but rather of psychiatric illness/diagnosis in the world of law. Yet the contemporary functional definition within the law remains inherently one developed by Victorian alienists. This often leads to complicated political response to the use of the incompetency defence in court, especially in high profile cases of political assassination (such as in the murder of President James Garfield by Charles Guiteau in 1881) or infanticide (the use of the

post-natal psychosis in the case of Susan Smith in 1995). In both cases the defence, using a version of the McNaughton rule, was unsuccessful. At least a few US states (Montana, Idaho and Utah) have now banned this defence (Millard, 2011; Rekers, 1995).

It is thus imperative to sort out what we mean when we use the categories of madness and psychic pain that define our object. Once we have settled on a particular definition/construct of madness, then we can ask how these limits impact on our understanding of those who are defined by these limits. Central to all definitions of madness is the idea of innate difference that is associated with it. This stereotype may be positive – debates about creativity and madness, for instance, go back to the ancients – but most have negative consequences. These include physically isolating the mad from society, refusing to give the same rights to the mad as to other citizens, and seeing madness as a diminution of one's humanity.

The Greeks regarded madness as the result of a physical imbalance of the four humours (black bile, yellow bile, phlegm, blood), the bodily fluids that they believed regulated health and temperament (thus they created melancholic, choleric, phlegmatic and sanguine temperaments and their attendant illnesses). The Chinese at the same time conceived of madness as an imbalance of the primal forces of *yin* and *yang*. Jewish beliefs, mirrored in the accounts in the Tanach (Old Testament), stressed moral failing and divine intervention as a primary cause of madness as in the case of Nebuchadnezzar (*Daniel* 4:31–3) but also, as in *Samuel* 10:6, the voice of the often unrecognized prophet. All these cultures placed the mad in a separate category: for some a higher one of prophecy and illumination but, for most, one of marginality and exclusion. All developed some types of therapeutic interventions for the latter, not necessarily for the former.

Roman and, later, medieval medicine and society made the distinction between the naturally born idiot and the lunatic, terms that overlap with and permeate medieval law and medicine. The former were not seen as treatable, but the latter were. The moral stigma and legal treatment of both, however, were clearly parallel. The question of causation mixed theological, physiological and mystical aetiologies, to varying degrees at different times and places. The means of treatment were similarly mixed: from spiritual exorcism to the use of somatic interventions such as diet to restore mental balance and physical control and to restrain the individual from actions that could harm their estates. This was also the case in Islamic medicine, which had transmitted much of Graeco-Roman social and medical attitudes on madness in the Middle Ages to Europe but which also was permeated by Christian and Jewish medical practice in Europe and beyond. Thus, Sura 4:5 of the *Qur'an* says: 'Give not unto the foolish what is in your keeping of their wealth, which Allah hath given you to maintain; but feed and clothe them from it, and speak kindly unto them.' This is a cultural translation of the Roman medico-forensic notions of 'furiosus' and 'non compos mentis' in limiting economic damage to an estate by a mad parent's fiscal irresponsibility, a notion that is itself linked to the theological understanding of madness from the New Testament (*Matthew* 4:24) (Robinson, 1998).

As the notion of the hospital evolved in the early Middle Ages, specialized institutions for the mad developed as early as AD 705 in Baghdad. This tradition had spread into Spain and Western Europe by the late Middle Ages. While a form of medical incarceration appeared for diseases such as leprosy and madness, the mad were rarely permanently housed in such facilities. Unlike lepers, who were understood to be contagious, they were usually incarcerated for a limited time, usually because of the costs to local communities for extended confinement, and then released. Leprosy and madness generated a sense of dread derived from the prevalent images of the leper and the insane. It was of little surprise that specific institutions grew up to socially isolate these sources of public anxiety. By the Renaissance, madness also became a conceit for the view that one's mad actions could be a sign of sanity in a world gone mad. As Shakespeare has Hamlet say (1601): 'I

essentially am not in madnesse, But mad in craft' (iii. iv. 171). This view of madness as a metaphor for sanity in an unstable world would become a commonplace of Romantic views of insanity and, indeed, part of the idea of madness thereafter.

By the nineteenth century in Western Europe the idea of a moral treatment of the insane as well as the isolation of the idiots, seen as inherently incurable, from the treatable lunatics was generally accepted. Moral treatment aimed at the return of the lunatics to their proper place in the world through the moral and secular correction of the misunderstandings of the world and their inappropriate actions. Thus, weekly dances for the inmates were a standard practice in the reformed asylum, to re-establish the moral order of their inmates. Led by lay directors, such clinical facilities gave way in the course of the nineteenth century to an ever-greater degree of medicalization across Europe and North America, so much so that by the close of the century asylum directors were virtually all medically-trained alienists. This development in treatment paralleled the professionalization of psychiatry and neurology and the creation of a systematic set of diagnostic categories as well as treatments. Most of these were based on physiological principles, though strongly psychological interventions paralleled them at the close of the century. Suddenly, madness as a category gave way to other terms such as 'affective disorder' as Bucknill and Tuke (1858: 125) state in their standard *Manual of Psychological Medicine*.

Even so, the nineteenth century placed its emphasis on somatic definitions of madness. Griesinger (1868: iii) wrote: 'The so-called mental illnesses are found in individuals suffering from brain- and nerve illness'. By the 1890s this view seemed to be universal in Western psychiatry. The neurologists of the time, such as the young Sigmund Freud, assumed this as a fact, but questioned the relationship between organic sources of madness and the wide range of psychological manifestations of mental illness. Freud began a movement, psychoanalysis, which accounted for the widest range of mental states as potentially leading to psychic pain yet without any direct organic cause. Indeed, Freud's great insight was that bodily symptoms, such as paralysis, could have purely psychological causes and should be treated by psychological interventions such as talk therapy rather than physical treatments such as electrotherapy (Gilman, 1993).

The somaticization of madness increased across the twentieth century, but it came at a cost. More and more symptoms were related to specific neurological deficits such as dementia. Development disorders were sorted out from illnesses with complex neurological causes – reductively dividing environmental diseases from genetic ones, for example – and thus further separating out those diseases seen as purely illness of the spirit, the psyche or the mind. Thus, the idiot and the lunatic, often housed in the same state institution through the nineteenth century, were by the early twentieth century seen as manifesting quite different social and medical causes (Trent, 1994). Indeed biological interventions such as sterilization dealt with such individuals, not to aid them but to improve society by eliminating their ability to reproduce. As the United States Supreme Court justice Oliver Wendell Holmes, Jr., concluded in affirming the Commonwealth of Virginia's eugenic sterilization law:

It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough. (*Buck v. Bell* 274 U.S. 200 [1927])

Biological definitions of madness generated a wide range of biological interventions to limit and control madness.

Yet the greater the detailed knowledge of the causes and meanings of madness the more the boundaries that defined it begin to shift. Thus, general paralysis of the insane, the most common

diagnosis for psychiatric patients in the nineteenth-century asylum, came to be recognized as the last stages of syphilitic infection, following the development of a specific test for the syphilis spirochetes in 1906; it thus became a potentially treatable neurological disease rather than a form of mental illness. After specific treatments for syphilis were developed, general paralysis of the insane simply vanished from the diagnostic repertoire of most physicians who dealt with madness and the treatment of its characteristic symptoms entered other medical specialties.

The desire in the twentieth century was to find more and more cases in which madness was the result of specific biological, neurological or genetic factors. Eugenic interventions, such as sterilization, came to be repudiated (if slowly) after the horrors of the Holocaust and its eugenically inspired mass murder of 'inferior races' as well as the disabled. Compulsory sterilization laws for madness existed in the USA from 1897 to well into the late 1970s and still occur in isolated cases, such as the California prison system, until today. In light of the Holocaust, post-World War II medicine sought specific bio-medical interventions (mainly psychotropic drugs) that could have an impact on the symptoms of madness, then defined in terms of psychosis (a lesser or greater loss of the psychic connection to reality) and neurosis (the impairment of rationality that leads to psychic pain) (Shorter, 1998).

Developmental disorders seem to have been bracketed in the search for a drug to cure madness. Yet the discovery of DNA in 1952 and the subsequent discovery of the specific mutations for Down's Syndrome in 1959 were more or less simultaneous with the first uses of lithium to treat the symptoms of depression and Thorazine (chlorpromazine hydrochloride) in 1950 to treat the symptoms of schizophrenia. The idea that there could be a genetic intervention to prevent all such developmental disorders is also an artefact of this post-World War II science as much as the now seemingly universal use of psychotropic drugs, from that first anti-psychotic medication in the 1950s to mood enhancers (Prozac) to drugs to treat hyperactivity (Ritalin). The expansion of drug treatment was first heralded by patients and physicians alike as effective interventions, but quickly became a target of patient and social discontent given massive side-effects as well as the over-prescription of many such drugs to ever widening categories of individuals. Madness seemed to become quotidian, and yet the stigma of madness remained.

With the expansion of psychotropic drug use, the patient self-consciously became the client and, with such shift of definition, became more and more self-aware. Twentieth- and twenty-first-century patient populations are now, in effect, consumers of medical care, and as consumers they organize and make demands – demands that range from the call for de-institutionalization and the closing of large public facilities housing individuals believed to be unable to function in the world to the desire to be released from the negative stigma of madness.

The rise of a contested science of madness in the nineteenth century provides a basis for the medical treatment of mental states as illnesses in the systematic classification of forms of mental (and other) illness. Begun in 1893 by Jacques Bertillon as a positivistic description of illness based on observable symptoms and analogous to his work in criminology, this soon became a global phenomenon. Revised in 1898 by the American Public Health Association as the *International Statistical Classification of Diseases, Injuries and Causes of Death* (ICD) it was only after 1948 that the World Health Organization's *International Statistical Classification of Diseases and Related Health Problems* appeared. It became the gold standard for international psychiatric classification, especially after its 8th edition of 1968. In 1973, the *Diagnostic and Statistical Manual of the American Psychiatric Association*, which had first appeared in 1952, assumed a global role in unifying the terminology for psychiatric classification. What was remarkable about these widely accepted means of describing mental illness is that they codified the contemporary views and attitudes towards madness globally rather than locally. By doing so, they claimed a scientific uniformity that existed only within their own closed systems.

In the 1960s, alternative perspectives on madness began to emerge in the works of Erving Goffman, R.D. Laing and Thomas Szasz, offering a re-examination of the social causes of madness. These had a powerful impact on the de-medicalization of madness among feminist and gay activists in the 1970s. Where Goffman (1961) saw the asylum as a repressive means of social control, Szasz (1961) saw madness as invented by the patient as well as society. Laing (1965) saw madness as the 'healthy' product of sick social or familial structures. All these models contributed to the growing patient empowerment movement of the time and began to shape the idea of disability beyond the medical model of rehabilitation (taken from interventions related to deafness and blindness) that had dominated the field from the eighteenth century (Stiker, 1999). The idea of a relativization of madness (now freed of any medical implication) first appeared in sociological work in France in the work of Georges Canguilhem in the 1940s and, later, with his student Michel Foucault in the 1960s. In *Folie et Dérison. Histoire de la folie à l'âge Classique* (1961), Foucault dismissed the antithesis of sanity and madness as the result of medical power (Foucault, 2006). One concrete result was that entire categories of madness such as homosexuality (in 1973) and premenstrual syndrome (in 1987) came to be dismissed from psychiatric diagnosis. More generally, the very idea of madness came to be suspect as stigmatizing rather than diagnosing.

Medical discourses of rehabilitation and disability inspired the creation of the category of psychiatric disability following the definition of disability as the result of illness in the 1980 World Health Organization's *International Classification of Impairments, Disabilities and Handicaps*. Thus, a psychiatric disability can be the result of a psychiatric impairment, which can be the source of the stigma of madness that impinges on the ability of the individual to function in the community. Different from other disabilities, such as developmental disabilities, psychiatric disabilities are seen as episodic and intermittent. But here the acknowledgement of the causality of the stigma of madness does not touch the underlying medical assumptions about the meaning of madness.

One reaction to this medicalized model of disability within the disability rights movement (and its allied academic field of disability studies) is to begin to see all forms of mental ability and emotional stability as ranged on a spectrum. The concept of a spectrum of human psychological/mental diversity came as an answer to the older model of psychiatric disability. Harvey Blume coined the term 'neurodiversity' in 1998 as a defining quality of being human: 'Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favor a somewhat autistic cast of mind' (Blume, 1998). This followed from work in disability studies that spoke of the 'extraordinary' body (Garland-Thomson, 1997), the 'rejected' body (Wendell, 1996) or the 'recovering' body (Couser, 1997) or, more recently, the 'problem' body (Chivers and Markotic, 2010). Disability thus dealt with the 'reception or construction of [the] difference' presented by a 'physical or mental impairment' (Davis, 2000: 56). Here one suddenly has the idea of the extraordinary, rejected, recovering or problem mind.

Such ideas of madness and disability develop parallel to the growth of popular interest in autism, which also comes to be the litmus test of the new test case for madness within disability studies. As Hellker and Yergeau (2011: 485) note, 'Public awareness and public discourse about autism are approaching critical mass.' Medically, autism has been defined as a psychiatric category since the early twentieth century. It is now seen as a developmental disorder with genetic or environmental causes. Certainly the flawed claims about MMR vaccination as the cause of autism coloured its re-evaluation at the end of the twentieth century by stressing the potential elimination of autism through social action rather than through genetic or medical intervention.

Today autism is increasingly seen as an alternative, even a preferred mental state, rather than as a deficit. It is the answer to Eric Fromm's view that madness in modern society is a sign of humanity's fall from 'biophilia', that is, from a sense of relatedness, rootedness and orientation (Fromm,

1955). Autism has come to be a sign that individual autonomy can challenge and often overcome notions of social isolation (Murray, 2012). The fascination with idiot savants in the late-twentieth-century public sphere (such as the autistic Raymond in Barry Levinson's 1988 film *Rain Man*) gives way to a new focus on the autistic individual as a representative of neurodiversity. Asperger's Syndrome is the new norm, exemplified by the 2010 film *Temple Grandin*, Mick Jackson's biopic that describes the youth of Temple Grandin, the iconic autist who is a professor at Colorado State University, and by Max Mayer's *Adam* (2009), the account of a young man suffering from Asperger's Syndrome. This framing of autism draws on debates about the autonomy of the client/patient from the 1960s and the image of a broader spectrum of mental health held by disability studies scholars. It rejects any sense of the autist as being severely impaired and in need of special facilities, only differently enabled. Indeed, both activists and scholars of disability have promoted the growing sense that autists are actually better enabled in a world that does not recognize their abilities. This is the theme of the best-selling 2003 novel by Mark Haddon, *The Curious Incident of the Dog in the Night-Time*. (See the various positions in the special issue of the *Disability Studies Quarterly* on neurodiversity devoted to autism; Savarese and Savarese, 2010.)

The need for public facilities for severely impacted autistic people has diminished as quickly in the twenty-first century as it did for the mad in general during the 1960s. The source of this decline is the sense that autistic individuals must function as part of a newly redefined public sphere that, according to law and custom, is now open to them, no matter how severe their individual state. The model for this is the treatment of Asperger's Syndrome rather than severe, debilitating autism. Thus the politics of disability and madness can be clearly seen in the debates about autism in the twenty-first century. The Americans with Disabilities Act (1990) defines disabling madness as 'any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities' that 'substantially limits one or more major life activities of an individual' or that cause one to be 'regarded as having such an impairment'. Both aspects of this definition assume a psychiatric diagnosis. The British Disability Discrimination Act (1995) follows the standard handbooks of psychiatric diagnosis as well as the idea that such forms of mental illness must be chronic or recurrent.

In 2011 the Neurodevelopmental Work Group, led by Susan Swedo, MD, senior investigator at the National Institute of Mental Health, was tasked with revising the category of autism in the standard American diagnostic handbook of psychiatry, the *Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5)*. They first suggested that the definitions of autism spectrum disorder be reworked and simplified. In DSM-IV, patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder not otherwise specified. It was proposed to unify and clarify these categories.

The reaction from the autism community in 2011, now well organized into political lobbying organizations with substantial fund-raising capacity and celebrity spokespeople, was swift and damning, seeing this medical decision as impacting on the funding for autistic clients as well as the exclusion of certain forms of autism from coverage in the law. The claim was that Asperger's syndrome and about 25% of those with other diagnoses of autism would not qualify under the new DSM-5 category. The psychiatrists who suggested the reforms to DSM-5 quickly backtracked, and the revision of the diagnostic category of autism spectrum disorders was again revised. When DSM-5 was eventually published in 2013, it reflected the political interaction between disability advocacy groups and the psychiatric community (Francis, 2013).

The autists who successfully put pressure the drafting committee for DSM-5 acted in complex ways. They demanded more medicalization (or at least reversing a trend toward de-medicalization) but at the same time they were able to exhibit their political clout as an interest group. Since the

drift of most disability activism is to de-medicalize disability, this is a counter-thrust. Neurodiversity is their cry, but they also want to preserve their medical coverage and legal protections. The medical model for madness is still potent even as the disability world begins to try to erode its power. The autists do erode the power of the medical community by putting pressure on them to reverse their decision, but the result is more rather than less medicalization. For autists as well as others diagnosed with mental illness or neurological disorder today, adopting the medical model of madness can still confer tactical advantage for some disability groups.

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