CHAPTER 8

Challenging Psychiatric Classification: Healthy Autistic Diversity the Neurodiversity Movement

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INTRODUCTION

Beginning after the Second World War, amid the momentum of civil rights, feminism and gay and lesbian rights movements, patients' rights groups began campaigning for their place in the human rights discourse. Disability rights activists engaged in aggressive campaigns for better access to services, while psychiatric patients and their families began lobbying for anti-stigma campaigns, alongside demands for adequate housing, basic health services, voting rights, and access to safe employment. The concept of 'mad pride' emerged in the 1960s and, like other pride movements, challenged the notion that madness, or gayness,

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or femaleness, was a disease to be treated rather than an identity to be celebrated.[1] At its heart, mad pride campaigns took aim at psychiatry for codifying mental health into a system of deficits and disorders that required medical interventions to fix, rather than look to political action as a mechanism for producing a culture of acceptance. The late twentieth century has been a time of expansion in both the utilisation of the diagnostic label of autism and the reach of the 'neurodiversity' concept, and we situate the work of this group in the context of previous patient movements.

Embracing 'madness' as a preferred term over ones such as mental disease, defect, disability, or illness reconnected an experience with an identity that was not necessarily the product of a medical encounter. Intellectuals in the 1960s began critiquing modern social values, in part, by analysing the history psychiatry and how it had evolved into a form of policing behaviour. They held psychiatry accountable for passing judgement on human value and in harnessing their practice to a political system that equated human worth with productivity.[2] Classifications systems, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM), they argued, merely institutionalised a practice of pathologising undesirable or unproductive people.

Famously, French philosopher, Michel Foucault in his first book *Folie de la Raison* (1961), translated into English under the title, *Madness and Civilization* (1965), trenchantly critiqued the rise of psychiatry and how it psychiatrised and attempted to control normal behaviour.[3] Madness, for Foucault, not only existed as a state that predated the rise of psychiatry as a discipline, but was also reminiscent of a point in time when mad people had a small degree of autonomy and when madness itself was part of one's character, not an affliction, label, or burden. Foucault lamented the rise of a modern world where psychiatrists wielded significant and, in his view, illegitimate power to determine what was and what was not acceptable behaviour. In a society where free will was leached away by modern aspirations of productivity, capital accumulation, and moral authority, Foucault critiqued how this world order created opportunities for individuals to police normalcy and to discipline members of society. His influential work on this topic ricocheted through the intellectual community and contributed to the rise of anti-psychiatry during the 1960s.

Some contemporary critics, including Thomas Szasz, a psychiatrist ultimately based in California, pronounced that 'mental illness was a myth', which had no basis in scientific or medical reasoning.[4]

The evolution of an 'anti-psychiatry' perspective, which sometimes cross-fertilised with post-modernism, provided fodder for critiques of psychiatry and its institutions. Another 1960s critical scholar, Erving Goffman, focused his doctoral work specifically on the way in which the institution itself produced abnormal behaviours, due to the disciplined existence within its walls, the rhythms of institutional life, and the reinforced labels that one was forced to adopt while 'playing a role' or meeting the expectations of a psychiatric diagnosis.[5] Scottish psychiatrist R. D. Laing added further grist to the mill by provocatively suggesting that madness offered insights into higher orders of consciousness; in other words, madness stimulated creativity, intelligence and allowed an individual to see past certainties held in check by the majority of society—the so-called sane.[6]

These academic critiques provided some of the intellectual, philosophical, and linguistic foundations for a more widespread social movement, which was populated by individuals who had consumed and survived mental health services (henceforth referred to as consumer/survivor movements). The timing was important. In the 1960s, governments throughout North America and Europe began closing, downsizing, and repurposing large psychiatric hospitals. Thousands of patients were moved into communities, unleashing a new host of challenges as former patients carried stigmatising labels, behaviours, and habits with them into communities that were often unwelcoming.[7] This major transition in mental health service provision—from asylum-based care to an undifferentiated matrix of health, welfare, education, and labour support—also gave rise to new forms of activism, as former patients and their families repositioned themselves in civil society.

Mad pride, the disability rights movement, the recovery movement, and other consumer/survivor movements emerged alongside these intellectual critiques of psychiatry and provided a poignant example of people denouncing psychiatric labelling and instead turning psychiatric experiences into sources of insight, authority, and expertise. The rise of consumer/survivor movements that ensued can be considered as a form of 'biosociality' a term coined more recently by Rabinow to describe common health identities linked by social networks.[8] What the new movements seem to share is a repudiation of 'victim' status and a push towards greater equality with those who are considered experts, clinicians, researchers, or professionals who become involved after diagnosis. They demanded a greater involvement in determining research priorities and policy decisions.[9] Thanks in part to these groups, the power

and credibility of their first-person voice—the voice of affected individuals—are increasingly acknowledged nowadays in health policy and clinical guidelines.

The 1960s patients' rights movements that relied on anti-psychiatry critiques have evolved considerably and have splintered and developed different approaches under the umbrella of social health activism. Today, one area of resistance to psychiatric labelling channelled by patients themselves is from those who have been diagnosed with neurodevelopmental conditions of childhood such as attention deficit hyperactivity disorder, dyslexia, Tourette's syndrome, and in particular autism. A politically mobilised group of adults with autism spectrum disorder (here referred to as ASD or simply autism), and sometimes their relatives, pioneered the neurodiversity movement (NDM). The NDM voice rejects society's disablement of difference while advocating a neurological/medical model for autistic behaviour. In this chapter, we examine the position of the NDM, with reference to other mental health consumer/survivor/patient movements and their challenges to psychiatric classification in the past.

THE NEURODIVERSITY MOVEMENT

> I am autistic. I've always been autistic, and I always will be autistic. Autism is part of who I am, just as my sense of humor and my emotions are part of me. I like who I am, even my autistic part.[10]

'Neurodiversity' is a concept that implies that neurological difference is best understood as an inherent and valuable part of the range of human variation, rather than a pathological form of difference. The NDM met and mobilised in the late twentieth century through utilising websites such as *Aspies for Freedom, The Autist, Autcom, Angelfire, Wrongplanet, and Neurodiversity.com,* most of which are based in the USA or Europe. Numerous online chat rooms, blogs, and fora are springing up where autistic adults discuss common interests and make friends across international and geographical boundaries. The rise of the internet in the late twentieth century enabled mobilisation and creation of online communities in geographically dispersed areas, occupying virtual social spaces that are constructed and normative in their effects.[11] Many autistic people started 'coming out' with pride, asserting minority cultural status, adopting similar strategies to the earlier gay rights movement. Many of

the arguments of the NDM relate to the autism diagnosis as a category or label. NDM voices taken from open access neurodiversity and autism sites are quoted here to illustrate their position.

The theory of labelling has a long history and activists and practitioners alike have struggled to come to terms with whether psychiatric labels help to reduce stigma and encourage research and treatment, or whether they merely reinforce a particular negative characterisation of behaviour that becomes a self-fulfilling prophecy. The neurodiversity movement in this respect is not unlike other survivor, consumer, or disability rights campaigns that both resist labels and rely on labels to forge a sense of community. Even amongst the most radical anti-psychiatry groups, the relationship with medical language has produced a common touchstone for identifying community and fostering a more positive image of identity. For example, Canada's earliest expression of organised mad pride emerged in the 1960s from a consortium of people who had been institutionalised for psychiatric disorders in Vancouver. As they discussed the appropriate name for their community-based group, they settled on Mad Patients' Association (MPA). The name blended philosophies of the de- or anti-medicalised term 'madness' with the explicit term 'patient', conveying a relationship with medicine. This self-conscious choice of names thus embraced the ethos of the survivors, or the radical edge of anti-psychiatric views—those who survived in spite of psychiatric interventions, and the consumer model—those who have relied on psychiatric services, from the perspective of an autonomous client or user.

Autism as a Diagnostic Category

Kanner and Asperger first described 'insistence on sameness' and 'autistic aloneness' over 70 years ago.[12] As was explained by O'Reilly, Lester, and Kiyimba in Chapter 7, according to today's DSM-5, autism diagnosis is given where there is (1) impairment in behaviours within the social/communication domain and (2) sensory issues and/or repetitive behaviours. Autism as a phenotype thus creates a category of persons who share social/communication impairment and repetitive behaviours, although the evidence that these symptoms are co-inherited is fairly weak.[13] Essentially, the diagnosis depends on a deficit-based description of a person, creating a 'spoiled identity' in Goffman's terms. Since the first epidemiological prevalence estimates were conducted in the 1970s

the autism diagnosis has seen an exponential rise, changing from a diagnosis given to an estimated one in two thousand to one in forty children. This rise is partly due to increased awareness and partly due to changing boundaries of diagnostic criteria, with intellectually able individuals included in the category of Asperger's disorder in the 1990s. Such changes, coupled with the advent of the internet, meant that for the first time, many twentieth-century children were identified with autism, and as they grew up, many had the means, the motivation, and the intellectual resources to challenge a purely medical understanding of ASD. In the 1990s, Martijn Dekker of the Netherlands founded Independent Living on the Autistic Spectrum (InLv), an e-mail list for autistic people. First run by hand on dial-up, InLv was the first fully autistic-run, self-hosted online autism community. The effect was to promote discussion of how autism could be a benefit as well as create challenges, fostering in its subscribers a 'healthy autistic' identity. The community became the forerunner to the NDM.

Autism is not currently identified by neurological markers as none are reliable enough to create diagnostic tests, although ASDs are classified as 'neurodevelopmental disorders' in the DSM. Despite the NDM's focus on the 'neuro', it is behavioural inventories that are used to diagnose ASD, not brain scans, and these use a dimensional scale of impairment with a cut-off rather than a dichotomous distinction. In the diagnostic process, the point at which individual differences in behaviour constitute autism is based on clinical decisions which may depend on resources that diagnosis will trigger, the meaning of diagnosis to the patient or clinicians' own ideas about signs and signifiers of autism. This, a somewhat arbitrary cut-off is used on the autism spectrum to define autism as a diagnosed disorder. This process is heavily influenced by culture, context, and values.[14] Chloe Silverman argues that the concept of autism as a diagnostic category has been established in the DSM and International Classification of Disease (ICD) and stabilised through the work of institutions such as schools, gene banks, professional associations, charities, government committees, parent networks, and those with vested interest in treatments.[15] The DSM and ICD systems are tools for classification of disorder that are themselves shaped by moral and historical values.[16] These aspects underscore the shifting nature of autism diagnosis and remind us that the idea of ASD as a fixed underlying biological/neurological entity (the purely medical model) requires qualification. Moreover, part of the pushback on these categories is coming from people who have been placed in them.

The Position of the NDM

The NDM has articulated a number of central features or core values, all of which stem from a denial of pathologisation and a critique of labelling as a harmful action against diversity. Each of these tenets is discussed below:

Opposing Elimination and Cure

Opposition to Cure of autism was frequently expressed as a rationale for online activity of NDM members:

> We are deeply concerned with the perception of autism as a disorder and the attempts to cure and prevent autism. In addition we are concerned about attempts to help autistic people that actually harm them. The purpose of this website is to educate the public about the anti-cure perspective.[17]

Michelle Dawson, a Canadian academic diagnosed with autism, has questioned the ethics of treatments such as applied behaviour analysis (ABA) and appeared as an expert witness in the 2004 legal case where parents of autistic children filed to get medical insurance to cover the cost of treatment, claiming it was a medical necessity. Her position was that ABA's techniques of aversion, which persistently expose children with ASD to stimuli that cause distress and subsequently discourage unwanted behaviours such as hand-flapping, are tantamount to cruelty. Dawson considers these unwanted behaviours to be coping mechanisms in stressful situations:

> Where ABA needs scrutiny is when its power is used to remove odd behaviours which may be useful and necessary to the autistic (such as rocking, flapping, and analytical, rather than social or 'imaginative' play); and when typical, expected behaviours which may be stressful, painful, or useless to the autistic (such as pointing, joint attention, appropriate gaze, and eye contact) are imposed.[18]

Others within the movement have criticised therapies, which attempt to remove autistic behaviours, claiming for example that the repetitive behaviours are valid attempts to communicate.[19]

> Neurotypical people pity autistics. I pity neurotypicals. I pity anyone who cannot feel the way that flapping your hands just so amplifies everything you feel and thrusts it up into the air. … A boy pacing by himself, flapping and humming and laughing. …A shake of the fingers in front of the eyes,

a monologue, an echolaliated phrase. All of these things autistic people are supposed to be ashamed of and stop doing? They are how we communicate our joy.[20]

In their opposition to 'elimination' and invoking the term 'genocide', the NDM has drawn on and shares a stance with the earlier 'survivor' movement. Similarly, people who were sexually sterilised under the eugenics programme in Alberta, Canada, have worked closely with community advocates and scholars to produce a 'survivor'-based website that examines the history of eugenics from their perspectives.[21] Survivors reject psychiatry outright, likening psychiatric treatment to a form of slavery and an outright abuse of power. Anthropologist Gabriella Coleman has suggested that some people have embraced that language of survival—much akin to the language of the NDM—strategically to underscore their resilience after decades, even centuries, of oppression.[22] The resulting movement, Coleman contends, 'mobilizes the cultural ideal of freedom and self-determination, along with the law of human rights and informed consent, to undermine the moral, scientific, and legal claims furthered by the pharmaceutical companies and other authoritative psychiatric institutions'.[23] Survivors represent the most radical voices within mad culture, connecting their survival, self-consciously, to a form of resilience. This terminology intentionally invites connotations of genocide by linking identity with a social group, such as a race or ethnicity.[24]

Use of Neurocentric/Medical Models
The NDM seems to have its roots in the social model of disability, which separates physical and biological impairment from the disabling attitudes and practices of society.[25]

> People with autistic spectrum disorders are not victims of autism, they are victims of society. They do not suffer from their developmental differences, they suffer from prejudice, ignorance, lack of understanding, exploitation, verbal abuse - all this and more from that sector of society which considers itself socially able.[26]

The NDM has also sprung from the twentieth-century trend dubbed 'neurocentrism' by Satel and Lilienfeld who define neurocentrism as 'the view that human experience and behavior can be best explained from the predominant or even exclusive perspective of the brain', which they

argue, has increasingly been adopted in parallel with the rise of neuroscience throughout the last half of the last century and into this.[27] Applying neurological explanations to one's mind has further been described by Rose as the 'neurochemical self'.[28] Neurocentrism is therefore a description of the extent to which neuroscientific theories, practices, technologies, and therapies are influencing how we view ourselves (those identities and characteristics ascribed to self and views of others). The term 'neurodiversity' implies the movement predominantly understand their differences in terms of innate neurology, the brain and/or wiring, perhaps underpinned with genetic causes. Language has been developed describing people as either 'neurotypical' (NT, not on the autism spectrum) or 'neurodivergent', i.e. people like themselves (non-NT). 'Neurotypical' is a term now widely adopted in academic neuroscience. The NDM, then, uses the language of brain wiring or neurology to explain the nature of their differences. The differences in how the brain communicates then result in behavioural differences. One NDM advocate explained it this way:

> Another common sign that someone is an NT? Touching. NTs enjoy all sorts of physical contact and often use touch to greet friends, family and even casual acquaintances… NTs are simply wired differently.[29]

As the autism phenotype is well-established, research coalesces around it. Neuroscientific research charts uniformities and abnormalities in the brain that make it possible to distinguish an autistic brain from a normal brain. Neuroscience seeks tangible, discrete differences between autistic and non-autistic brains while epidemiology tells us ASD is a spectrum condition extending into the sub-clinical range. In this way, neuroscience researchers tend to dichotomise brain structure for what is essentially a dimensional condition. By looking at differences between dichotomised autistic/non-autistic phenotypes (as opposed to a dimensional spectrum of traits in the whole population), medical neuroscience models tend to homogenise autistic brains.[30] This is analogous to the dichotomisation of difference between 'neurotypical' and 'neurodivergent' persons identified by the NDM; it refers to an essential difference in brain structure and/or functioning. Thus, the NDM adopts a position that both challenges and shores up medicalisation: while questioning autism and other neurodevelopmental conditions as diagnosable 'disorders', it utilises a model derived from neuroscientific research.

The rise of neurocentrism is transdisciplinary in its reach. Historian Daniel Smail has developed this idea as an overarching ontology that, if applied carefully, has the potential to disrupt our commonly held beliefs about diversity and difference over time. He proposes a 'neuro-historical' approach that locates the beginning of history at a moment when humans approach a state of consciousness; he defines this moment in neuro-biological terms as the evolutionary stage that separates humans from animals. Pinpointing this moment, he argues, requires careful collaboration with scientists to sift through new kinds of evidence—biological and neurochemical evidence—to re-interpret the origins of history. Part of Smail's justification for a turn to neuro-history is that it offers a deeper, richer account of humanity by acknowledging human bio[neuro]-diversity. He recommends shifting the historians' gaze away from political structures, social arrangements, or even cultural expressions and looking instead to neuro-history.[31] This conceptualisation of neurodiversity is not unlike some of R. D. Laing's suggestions in the 1960s that schizophrenia could be productively understood as an alternative form of consciousness. Rather than view psychotic symptoms as deficits or abnormal characteristics, Laing considered that delusions, paranoid ideation, and other kinds of behaviour might produce a form of intelligible insight into human interactions.[32]

Objections to Diagnosis as a Category of Disorder

Diagnosis of autism is recommended by health guidelines as an essential way to access treatments.[33] However, many autistic adults in the NDM feel that both experts and families misinterpret or take no notice of them.[34] Autism, they argue, should not be considered as pathological, i.e. in terms of a medical condition, but in terms of the normal variation of the human population; thus, many in their ranks oppose medical description in terms of diagnosis of an ASD.

> The autistic community firmly believes that autism is not a disorder but a natural human variation. We are deeply concerned with the perception of autism as a disorder.[35]

A core argument is that the extreme end of the autism spectrum (i.e. reaching diagnostic thresholds) is required for the existence of a healthy gene pool in the human population. Without these people, the range of natural human variation is reduced, and the strengths that autism brings,

such as ability to focus and systemising skills, will be lost. Such variation in the gene pool is desirable for evolutionary reasons, the NDM contest.

> It may be that autistic people are essentially different from "normal" people, and it is precisely those differences that make them invaluable to the ongoing evolution of the human race.[36]

This argument matches some of the historical anti-psychiatry arguments, particularly those of Laing, who suggested that people with psychotic disorders had a lot to offer society due to the gift of insight that they had into situations that non-psychotic people could not even appreciate. Within the neurodiversity movement, a similar sentiment circulates, suggesting that some autistic people also have particular areas of strength or talent formerly known in the medical literature as 'islets of ability'.[37] Members of the NDM point out that all these aspects of autism will be lost if people like them are 'cured' or aborted as babies.

> Many of the traits I identify with most strongly are those labelled autistic, such as the ability to hyperfocus, a strong attention to detail, the ability to enjoy my own company for long periods, not being controlled by the social collective, etc.[38]

There are several historical precedents where conditions have been de-medicalised in the past, through activism of politically mobilised social movements. The classic example of de-medicalisation in the twentieth century is homosexuality, which was listed as a disorder in the second edition of the DSM, becoming a treatable medical condition rather than a behaviour that had previously been seen as morally wrong. Hormone treatments and castrations were used to 'cure' homosexuality and in some cases admission to mental institutions.[39] While people were unsuccessfully 'treated' or punished for homosexual behaviour in the past, medicine now recognises it as a dimension of a normal and healthy life, thanks to sustained pressure from gay activists who mobilised around the diagnosis in the mid-century period.[40]

Parallels to the NDM objection to ASD as a devastating childhood disorder can be seen in the transgender movement's attempts to demedicalise gender identity disorder (GID) of childhood in the late twentieth century. Bryant and Burke describe in depth the opposition of the transgender movement (TGM) to this diagnostic category which first

appeared in DSM-III in 1980.[41] The main objections to GID diagnosis were that sex-stereotyped behaviour was used to define children as healthy or pathological, which reinforced the binary model of gender. The TGM objected that GIDs could result in stigmatisation of transgender individuals that gender variance was no longer described as a range of valid ways to be, but rather had been redefined as a serious form of illness. The movement drew attention to treatments that were designed to intervene and 'cure' individuals of their problem. A technical objection was that existing research and clinical evidence were based overwhelmingly on study and treatment of boys, an argument that has parallels with discussions about gender and autism.[42] Overall, the TGM raised similar objections to those of the NDM today.

Like the NDM, the TGM were vocal protesters and mobilised around the diagnostic category. After a concerted writing campaign to the American Psychiatric Association (APA, authors of DSM) in 1977, concerns and correspondence led to modifications in DSM-IV, where a less behavioural-based medical definition of GIDs was adopted. GIDs in DSM-IV were also subject to sustained activist objection. By the mid-1990s, several political US-based transgender groups, including Gender Pac, National Centre for Lesbian Rights, and National Gay and Lesbian Task Force, issued stinging statements critiquing GID. In 1996, activists repeatedly picketed the APA and formed the 'National Coalition for GID Reform', and finally in 2013, GID was dropped in the DSM-5 revised diagnostic criteria. The condition was replaced with a new category 'Gender Dysphoria' which only pathologises the discontent experienced as a result of gender identity issues. Some in TGM accept the new DSM-5 definition does go some way to demedicalise GIDs and helps to resolve some of their issues. Fraser, Karasic, Meyer, and Wylie, for example, argue that changes to DSM were a direct consequence of activism and have led to a more acceptable diagnosis/ label and a reframing of the condition as they see it.[43] One parallel NDM argument is that the term 'disorder' implies a pathological state, with negative and stigmatising connotations. Autism researchers have therefore called for the term 'autism spectrum disorder' to be replaced by 'autism spectrum condition', reminiscent of the replacement of the term 'retardation' with 'learning disabilities' in the 1970s.[44] This replacement of terms and continual refinement of diagnostic criteria is an important feature of the history of psychiatric disorders. However, as Jan Walmsley explained in Chapter 5, replacing terms does not always alter stigma indefinitely.

The new term may become stigmatised as its connotation may become the same as the old term. Even replacing autism with 'neurodivergent' is simply replacing one label with another.

Embracing Labels: Being or Having?
The NDM see autism as an integral part of their identity that they are disinclined to change. The autistic activist Jim Sinclair presented a talk called 'Don't Mourn for Us' at the 1993 International Conference on Autism in Canada, addressed primarily to parents. It drew interest through its challenge to the then-dominant 'autism as tragedy' narrative, describing autism as inseparable from the person, rather than a separate disease entity, and as a valid way of being. Following this influential paper and in contrast to the requirements in medical journals, the NDM often prefer first-person language 'autistic person' to 'person with autism' as the latter implies the autism can be divorced from the individual.

> Autism is not something that I have, it is something that I am. Autism is not a cage, with us as the prisoners.[45]

Many parents, by contrast, prefer the more medical term 'person with autism'. Kit Weintraub, a parent who is a board member of Families for Early Autism Treatment, states:

> My children are not autistic, they 'have autism'…. Autism, according to the vast majority of medical experts today, causes severely abnormal development, and without appropriate treatment it can condemn those affected to a life of isolation and dependency. "Autistics" is a rather new politically-correct term that I find troubling; it is a label that attempts to define people with autism as members of an elite group of human beings who differ from the rest of us only in terms of their unique talents and their superior way of experiencing the world.[46]

However, some autistic people have argued against this viewpoint. Michelle Dawson retorted that 'person with autism' was equivalent to describing herself as a 'person with femaleness'.

> Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person.[47]

Examining some of the online sources suggests that that parents, teachers, and even siblings are indeed present within the NDM community, but their relationship to the movement is different. Unlike the bold statements about *being* autistic, not *having* autism—parents fill a different role in their relationship to children who are considered autistic. This triangulating effect may force us to return to a different set of historical trends. That of familiar arguments about pre-natal screening, mother-blaming, food additives, and other environmental factors that cast the net over a much wider set of influences for contributing—whether positively or negatively—to the neurodiversity identity. American philosopher and psychiatrist Carl Elliot has described this cascading effect in terms of contagion or that of being 'sick by association' or courtesy stigma idea.[48] The resulting labelling of entire families or perhaps groups creates another layer of complexity as we examine the process of identity building and forms of activism that are created to challenge or embrace these labels.

For the NDM, although opposed to the notion that they suffer from 'disorder', the label of 'autism' has become both an identity and a rallying cry. Increasingly activism occurs online, and occasionally this becomes a physical meeting. In 1995, *Autreat* was founded. This is an annual conference that accommodates autistic difficulties, e.g. participants wear colour-coded badges indicating whether or not they may be approached for conversation. *Autreat* endeavours to create an ideal NDM environment that eliminates disablement through tolerance and adaptation and challenges the status of autism as a psychiatric disorder.

Diverse Perspectives Within Social Health and Survivor Movements

As the scholarship on this topic has illustrated, the approaches taken by social health and survivor movements are varied, complex, and change over time. The language of survival versus consumption provides one broad set of generalisations for understanding the political stances within this multifaceted set of movements. Even within organised campaigns, however, there is significant granularity that can range from libertarian to socialist perspectives regarding how people should be cared for, accepted, and tolerated in modern society. Within debates over the medicalisation and treatment of addiction, for example, scholars and practitioners

continue to disagree on whether the twelve-step model of recovery developed in the twentieth century offers a sufficiently de-medicalised approach, or whether it should be used at all. Some have suggested that individuals need a menu of treatment options that might change over time, which superficially may appear as though they subscribe to different models of addiction altogether.[49] The fluidity, however, is important in these rights-based campaigns as individuals develop different relationships with practitioners, services, and gaps in the mental health system.

Similarly, the position of the autistic community vis a vis diagnosis of autism is not homogenous. While some activists argue that the diagnosis of autism spectrum 'disorder' implies a pathological state, with negative and stigmatising connotations, many other adults describe their relief and understanding once a diagnosis is given; a label that makes sense of a lifetime of struggle. High profile cases have included Susan Boyle who described her relief at getting an Asperger's diagnosis, which for her, provided an explanation of her difficulties, and deflected attributions of responsibility for previous aberrant behaviour.[50] Thus, the diagnosis can have a positive effect, whereas undiagnosed, a person may have been blamed as lazy or socially tactless: diagnosis may lead to attribution of behavioural difficulties to biomedical causes, which improves others' reactions.[51]

Autism is highly heterogeneous, and individuals may range from severely intellectually impaired and/or non-verbal to 'high functioning' and articulate. Detractors of the NDM argue the online self-advocates represent only the high-functioning extreme. Indeed it may be the medicalisation of less severe autism behaviours that has ironically given impetus to the NDM, as less severely impaired individuals have rallied under the autism banner, where previously they may not have been diagnosed. Francisco Ortega, describes the movement as a form of aggressive identity politics who appropriate the right to speak on behalf of every autistic person.[52] It is certainly true that not all adults diagnosed with autism see their condition as a positive part of themselves, and some are pro-cure.[53]

> The possibility that I could be very autistic for the rest of my life always upsets me. Therefore, when people talk about a cure I actually love to hear it. To be realistic, I know I will never be cured. The cause of my autism is a genetic anomaly and can't be changed.[54]

Whether or not total de-medicalisation of autism is a desirable outcome, there are powerful forces at work that oppose this. The fact that autism is such a well-recognised phenotype with invested research, clinical and commercial worlds reliant on its existence as a medical category adds to the entrenchment of the category. Cooper describes this process and argues this makes major de-medicalisation by DSM unlikely.[55] This uncomfortable relationship with medical terminology, treatment, and a simultaneous rejection of a disordered identity is a familiar tenet of many of the social health movements and illustrates some of the inherent tensions within these campaigns.

CONCLUSIONS

The NDM movement is an example of the kind of authentic expression that attempts to take mental health and disability conditions out from clinician's control. It both uses and challenges the medicalisation of brain and behaviour in a way that offers a coherent and consistent critique of psychiatry while allowing for diversity within its members. Broderick and Ne'eman argue that the bulk of the support for framing autism within a disorder model, where it is viewed as a 'disease' external to the person comes from within the non-autistic 'NT' community, whereas the bulk of the support for framing autism within a neurodiversity model comes from within the NDM and autistic community.[56] They argue that NDM provides a counter-narrative that can play a vital role in the resistance to ideological hegemony (which they view as the medical model of autism diagnosis). They position the NDM are essentially activists in the process of de-medicalisation of autism.

However, we have found that instead of providing a homogenous oppositional set of ideas, the NDM have struggled to define their relationship with psychiatric categories much like other consumer campaigns that adopt aspects of the medical model, while rejecting wholesale psychiatric classification. Far from being a standardised voice, the NDM is also typical of other social health movement in the complex identity politics that co-mingle with the psychiatric labels, those of gender, age, sexuality, race, class amongst others, which continue to condition individual experiences.

The early phase of mad pride movement in the 1960s relied on a more homogenous notion of madness to anchor its resistance from institutionalisation and opposition to psychiatry borrowing strategies from

the left, namely collective action, and from the right, especially elements of libertarianism. As the movement evolves, however, as with other social movements, identity politics have grown more complicated. The NDM provides an illustrative example of how some of those struggles have played out in a particular manifestation of experiences, ones brought together through a degree of commonality. Digital media technology, used very effectively by the NDM, also demonstrates a new layer in the discourse on consumer networks as unlike the 1960s where people needed to physically gather to generate a common set of political goals, and the internet allows for virtual meeting spaces and virtual identities.[57] It helps to complicate boundaries of citizenship and identity and offers, perhaps, a new model for consumer-survivor activism for the twenty-first century.

Notes

1. We believe the first mad pride march took place in Vancouver, Canada in 1963. It was a very small event, so small that organisers barely remember it taking place. But small though it was, it helped to put madness on the map in terms of human rights movements in the 1960s. See, "*The Inmates Are Running the Asylum*," youtube.com (2013).

2. For example, see Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason* (New York: Vintage Books, 1965).

3. Ibid.

4. Thomas Szasz, *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct* (New York: HarperCollins, 1974).

5. Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (New York: Anchor Books, 1961).

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