

Chapter 8

Listening to Those with Lived Experience



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Introduction

One of the most important critiques of the dominant model of biomedical psychiatry comes not from psychologists or other mental health professionals but from individuals who have experienced emotional distress and have been given psychiatric diagnoses and/or psychiatric treatment. In the critical psychiatry academic discipline and activist community, these individuals are often referred to as “people with lived experience.”

Many scholars, advocates, and activists with lived experience have spoken or written about psychiatry’s colonizing effect on their identities. According to the American Psychiatric Association, psychiatry is “the branch of medicine focused on the diagnosis, treatment and prevention of mental, emotional, and behavioral disorders” [3]. Arguably, psychiatry constitutes a system of categorizing individuals as mentally disordered or mentally healthy; the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) serves as a framework to define the types of internal experiences and

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outward expressions that are pathological. Within this framework, psychiatrists and other mental health professionals are seen as the experts on the value, meaning, normality, healthiness, and rationality of their clients' experiences. The mainstream model of psychiatry is one in which clients tell their psychiatrists about their experiences and then are provided with the diagnostic terminology, language, and paradigm through which to understand them. Clients are taught to see their experiences as symptoms that need to be managed through one or more forms of treatment.

Scholars, advocates, and activists have critiqued this model of psychiatry on the basis that it provides little room for people with lived experience to come to their own understandings and conceptualizations of their internal states and outward behaviors. Many people with lived experience find meaning or value in their so-called symptoms and prefer to approach their distress and/or differences in a non-pathologizing way. Clients may, for example, view their experiences not as illnesses in need of treatment, but instead as positive aspects of their identities, rational reactions to traumatic circumstances, temporary states that will pass with time, or all of the above.

People with lived experience have developed a number of alternative frameworks for conceptualizing distress and difference. Two frameworks that this chapter will focus on are the principles of Mad Pride and the field of neurodiversity. The field of neurodiversity seeks to redefine thoughts, feelings, characteristics, and traits categorized as symptoms of mental disorders as naturally occurring, valid forms of human diversity. Similarly, the Mad Pride movement is made up of people with lived experience who find value and even pride in their experiences that have been constructed as madness or mental illness. Central to both of these paradigms is the notion of people with lived experience deciding for themselves what terminology and meaning they would like to ascribe to their own states and characteristics.

This chapter will discuss some of the primary principles, ideas, and tenets of both the Mad Pride and the neurodiversity movements. It should be noted that not all Mad Pride and

neurodiversity activists share the same views; in fact, both movements could be described as loose coalitions of individuals and organizations rather than unified campaigns. This chapter does not aim to capture the views of all Mad Pride and neurodiversity activists but instead some of the principles behind the development of both movements. It should also be noted that there are significant differences between the Mad Pride and neurodiversity movements, but this chapter will focus on similarities.

Questioning Dominant Assumptions

Both the Mad Pride movement and neurodiversity field radically question some of the fundamental assumptions underlying the traditional model of psychiatric care. Both paradigms call upon mental health professionals, researchers, advocates, and the public to re-examine some of their beliefs about what we consider madness or mental illness. Below are some of the assumptions the two paradigms seek to challenge.

That Which We Consider Madness Is an Illness That Needs to Be Cured or Managed

Many Mad Pride and neurodiversity advocates argue that the states and characteristics that we categorize as madness are not illnesses that need to be prevented, treated, or cured, but rather part of the human experience. They often view feeling emotions intensely, experiencing auditory or visual hallucinations, and being highly sensitive as part of the continuum of differences that make humans uniquely themselves. These experiences are seen as just some examples of the characteristics that make up each person's idiosyncratic way of responding to the world around them.

Rather than referring to themselves as "mentally ill," many neurodiversity advocates refer to themselves as "neurodivergent," i.e., having a brain or personality that differs from what is perceived as normal. People who do not have traits or characteristics

categorized as mental illness may be referred to as more “neurotypical” or “neuroconforming” to reflect the notion that their cognitive styles, emotions, and behaviors are perceived as being more typical or more conforming to societal norms, rather than mentally healthier with better functioning brains. In the Mad Pride and neurodiversity frameworks, divergence from the norm and diversity of thoughts, feelings, and internal states are seen as positive, just as we generally view cultural, racial, ethnic, and gender diversity as positive.

In speaking about the value of her own lived experience, neurodivergent activist Darien Rachel Welch says, “I think the value in neurodivergence is being afforded the opportunity to experience life on the other side of acceptance. Having to play with what that means while constantly being taught that you are broken, on a regime to be fixed. Being impervious to the standard glyph of human behavior and recognizing how flawed and dangerous it is. I see people labeled as neurodivergent sustaining what makes them unabashedly human in a society that demands their conformity” [37].

Madness Is an Objective, Discrete Category. People Can Be Proven to Be Either Mad or Sane

Mad Pride and neurodiversity advocates also emphasize the culturally constructed, rather than objective or binary, nature of madness and neurodivergence. They seek to challenge the notion that a person is either mentally healthy or mentally ill by pointing out all of the social and systemic factors that shape a person’s likelihood of being placed in one of these two categories. For example, in some geographical locations and time periods, being queer or questioning one’s sexual orientation is or has been seen as a sign of mental illness; in other contexts, queerness is not or has not been pathologized. Additionally, in some cultures, experiencing auditory hallucinations is seen as a religious experience and a sign that a person may be spiritually gifted; in other cultures, experiencing auditory hallucinations is seen as a sign of schizophrenia.

Mad Pride and neurodiversity advocates also highlight the ways that a person's individual life circumstances may intersect with broader societal factors to shape whether they are or are not considered mentally ill. For example, in a variety of cultures and contexts, mental health clinicians would not diagnose a parent who has just recently lost a child and is experiencing sadness with major depressive disorder. Yet, a parent who continues to experience a predominantly sad mood after 5 years may or may not receive a diagnosis depending on contextual factors, such as cultural customs and definitions of appropriate grieving, as well as a clinician's individual views and diagnostic preferences. What about a situation in which a parent who has just recently lost a child has begun to experience auditory hallucinations? Whether or not this parent is categorized as mentally ill would also depend on contextual factors and a clinician's individual judgment. The same factors apply to situations in which an individual meets the diagnostic criteria for a mental disorder after a breakup, divorce, job loss, or other major life transitions. Mad Pride and neurodiversity advocates point out these various contextual factors in order to demonstrate that whether someone is deemed mentally ill does not depend on objective, discrete pathology but on clinical and societal judgments around what constitutes rationality and normality.

That Which We Consider Madness Is Dangerous

Many dominant psychiatric and societal ideas about the experiences categorized as madness assume that these experiences are dangerous. The notion of just letting people experience the so-called symptoms of mental illness without receiving treatment often leads to the question, "But what if someone ends up getting hurt?"

Mad Pride and neurodiversity advocates point out that people diagnosed with mental illness are no more likely to be violent than anyone else. In fact, people diagnosed with mental illness are more likely to be victims of crimes than perpetrators [15]. Additionally, there are many traits and experiences

that *are* associated with a risk of danger – such as extreme sports, sleep deprivation, and risky sexual activity – and are not categorized as signs of mental illness or madness. While some individuals do commit violence precipitated by hallucinations or extreme states, this is not a reason to categorize all hallucinations or extreme states as signs of mental illness, any more than engaging in extreme sports should be seen as a sign of a mental illness due to motorcycle racing deaths.

That Which We Consider Madness Is Uncommon or Abnormal

One of the underlying assumptions of the psychiatric paradigm of care is that the traits and experiences categorized as mental illness are uncommon. Part of a psychiatrist's or mental health professional's job is to determine whether a client's experiences are phenomena shared by the majority of people or whether they are abnormal. While neurodiversity advocates do not focus as much on challenging this particular assumption, Mad Pride advocates and scholars seek to show the ways in which that which we consider madness is, to some extent, a universal experience.

For example, many Mad Pride advocates have spoken about the ways in which hearing voices is more or less a universal phenomenon. Whether we experience horrifically self-critical internal voices or antagonizing external voices, many of us relate to the experience of being told insulting messages by different parts of ourselves. Additionally, everyone experiences life hardships, losses, and obstacles that can lead to intense sadness and pain as well as even apathy, mania, and hallucinations for some [1, 32]. Mad Pride activists point out that in finding meaning and value in that which we consider madness, we are not only making the world more inclusive to those diagnosed with mental illness, we are also giving everyone a bit more freedom to experience and express emotions and idiosyncrasies without being stigmatized or pathologized. A core principle of the Mad Pride

movement is that rather than conceptualizing distress and difference as a justification for othering a person or categorizing them as abnormal, we can view a person's distress or difference as an opportunity to connect with and relate to them. In accepting and embracing our shared vulnerability, we can pave new paths to forming more meaningful relationships and communities.

That Which We Consider Madness Is Irrational

Another underlying assumption of the traditional model of psychiatric care is that the experiences categorized as mental illness represent an irrational way of thinking, feeling, or behaving that needs to be corrected and adjusted. Many Mad Pride and neurodiversity advocates seek to convey that which we consider madness as a natural, rational reaction to external circumstances. Numerous written and spoken testimonies by people with lived experience speak to the roles that trauma, oppression, and life hardships play in causing emotional distress and extreme states [14, 18, 21, 22, 35], [25].

Mad Pride and neurodiversity advocates tend to support trauma-informed care, a paradigm whose core principle is to ask not "What's wrong with you?" but "What happened to you?" In the paradigm of trauma-informed care, the definition of trauma is not limited to physical acts of violence and sexual abuse, although these forms of violence can certainly play a major role in leading to distress and extreme states. Trauma-informed care also considers the role of societal oppression and systemic injustices in affecting our well-being; individuals who practice and advocate for trauma-informed care recognize that not only overt forms of discrimination and hate but also more subtle forms of bigotry, such as microaggressions and social exclusion, can drive individuals to experience what we consider madness. Additionally, they recognize the role that economic hardships and class factors can play, ranging all the way from the burden of living in poverty to the pressure upper middle-class individuals might feel to be successful and

maintain their status. Furthermore, trauma-informed care acknowledges the impact of life hardships, including not only death and loss but also breakups, divorce, unemployment, and workplace stress.

In short, Mad Pride, neurodiversity, and trauma-informed care recognize that life is difficult for everyone, and any reaction or response to life's hardships is understandable and can be seen as rational. Mad Pride and neurodiversity advocates usually do not see it as helpful or constructive to judge which kinds of reactions and coping styles are valid and which are disproportionate to an individual's circumstances. Instead, their goal is to validate all reactions to our often painful and burdensome existence.

That Which Is Uncommon Is Unhealthy

Another assumption underlying the psychiatric paradigm is that a trait's abnormality or rareness in society potentially signifies that it is a symptom of mental illness. While some amount of suffering, quirkiness, or divergence is to be expected, one of the purposes of the DSM is to capture those whose differences veer unacceptably or unhealthily far from the norm. Abnormality in of itself is seen as pathological.

The Mad Pride and neurodiversity frameworks argue that just because one trait might occur less frequently than another trait in society, that does not necessarily correlate with the healthiness of either trait. English speakers are not any healthier than French or Italian speakers; white people are not any healthier than people of color. One prime example of this, of course, is people who identify as LGBTQ. Although homosexuality was once pathologized in the DSM due to its rareness or minority status, we now know that being queer is not necessarily associated with increased suffering, apart from the societal oppression LGBTQ individuals experience as a marginalized group.

Mad Pride and neurodiversity advocates often pose the question: What else might the DSM pathologize that is not

necessarily correlated with suffering, apart from societal oppression? While the DSM no longer pathologizes homosexuality, many people with low sex drives are diagnosed with hypoactive sexual desire disorder or inhibited sexual desire. Yet, one can easily discover in the literature about, and activism of, the asexual community that for many people, having a low sex drive is not at all problematic in of itself [6]. Theoretically, the diagnoses of hypoactive sexual desire disorder or inhibited sexual desire do not apply to asexual people; the DSM states that these diagnoses cannot be given to people who identify as asexual or to people who feel their low sex drive is not interfering with their lives or causing them any suffering. However, for many individuals, it may be nearly impossible to separate the effect of societal biases against a particular trait from inherent suffering correlated with that specific trait. For example, people who have been told that they need to have a high sex drive in order to conform to their prescribed gender roles or be good spouses might experience low self-esteem and negative effects on their well-being. They may not wish to identify as asexual and may instead hope that their low sex drive is fixed or changed. For this reason, a diagnosis of hypoactive sexual desire disorder or inhibited sexual desire might be given, despite the fact that some people's low sex drives might not have caused them problems apart from societal pressures and biases.

The Mad Pride and neurodiversity frameworks strive to examine all diagnoses through this lens. For example, experiencing hallucinations might not in of itself be problematic or cause suffering. Some accounts from people who experience hallucinations, however, speak to the content of their hallucinations worsening and becoming more distressing as a result of societal stigmas and biases against these experiences [9, 21]. Similarly, many autistic people report not experiencing distress resulting directly from their autism, but have experienced significantly increased levels of distress resulting from discrimination, exclusion, and societal pressure to act less autistic [20, 28, 34]. Numerous accounts written by autistic advocates focus on the trauma that has resulted from their experiences of applied

behavior analysis (ABA), a therapy designed to reduce the behaviors associated with being autistic [5, 29].

As mentioned above, Mad Pride advocates often acknowledge that the traits that are constructed as madness or mental illness are actually much more common (or even universal) than we are led to believe by the psychiatric paradigm. Growing acceptance of the LGBTQ community has led more people to come out and identify as queer; even those who identify as straight may view their own orientations as more fluid than people did in the past, and the public is generally more open to a range of experiences with and conceptualizations of gender and sexuality. Similarly, destigmatizing and depathologizing mental distress and differences may lead to more people “coming out” and identifying with these phenomena as well as recognizing how even some of the experiences that we do not consider mental illness – such as internal voices – can be viewed along the continuum of mental diversity.

At the same time as recognizing and promoting this message of universality, though, both Mad Pride and neurodiversity advocates emphasize that the healthiness or validity of a given experience or trait should not *depend* on its universality or commonality. Even if only a very small percentage of the population identified as LGBTQ, being queer would not be pathological. Correspondingly, even if only a very small percentage of the population experiences the traits and characteristics considered to constitute madness, those traits and characteristics are not necessarily pathological. A trait’s prevalence within the general population should be considered separately from its healthiness.

Mad Pride and Neurodiversity in Action: Examples

Individuals with a variety of different mental, cognitive, emotional, and behavioral experiences have conceptualized their own identities in alignment with the Mad Pride and neurodiversity frameworks. Below are four examples of how these frameworks have been employed.

A Mad Pride/Neurodiversity Approach to Auditory and Visual Hallucinations and Extreme States

As mentioned above, many people who experience hallucinations and extreme states, such as mania and depression, do not consider these characteristics to be inherently pathological, instead viewing these phenomena as positive aspects of their identities. Some view their hallucinations as helpful influences on their lives, guiding and encouraging them and/or ensuring that they never feel alone. Others take a more trauma-informed approach, conceptualizing distressing hallucinations as reactions to trauma; while these experiences may not be framed as positive or enjoyable, they are still seen as valuable and helpful because they may alert the individual to unresolved trauma. Still others have a more spiritual perspective on hallucinations and extreme states, conceptualizing them as part of being spiritually awakened; for example, some people find that the state we call “mania” allows them to feel more spiritually connected.

The Hearing Voices Network (HVN) is an international organization that provides and advocates for non-pathologizing approaches to hearing voices, seeing visions, and other unusual perceptions. Although many HVN members have been diagnosed with schizophrenia or bipolar disorder, they may not identify with their diagnosis and instead refer to themselves as “voice hearers” or “people who experience extreme states.” One can find Hearing Voices groups across the USA and abroad in which voice hearers and people who experience extreme states come together to talk about and find meaning in these phenomena as well as provide one another with support. People hearing distressing voices, for example, may be supported in listening to and engaging in dialogue with those voices to better understand what their experiences might mean. They may find that the voices represent perpetrators of trauma that has not yet been processed, intense emotions they have been too afraid to speak about, or friends or family members whose deaths they have not fully grieved.

Additionally, some HVN members may interpret their hallucinations or extreme states as coming from external sources such as deities, spiritual entities, or extraterrestrial beings. While not all HVN members share the same spiritual belief systems, group members are respectful of one another's beliefs and understandings of their experiences. Hearing Voices groups support members in coming to whatever interpretations of their voices is most helpful and feels most truthful to them.

Autism: Divergence, Not Disorder

The neurodiversity paradigm was developed primarily by autistic advocates and scholars who view autism as a way of being and existing in the world that is not pathological or disordered. Many autistic advocates point out that the traits and characteristics categorized as autism do not inherently cause suffering apart from the demands of the society in which we live. For example, autistic styles of communication – such as not making small talk, employing more blunt or direct expressions of needs, and using text-to-speech technology or sign language in the place of oral speech – can be viewed through the lens of cultural differences rather than deficit or disorder. If an immigrant has difficulty grasping the norms and customs surrounding communication in the USA, we would not conclude that the immigrant is disordered, but rather is accustomed to a different cultural style of communication. Similarly, the neurodiversity paradigm recognizes autism as a different cultural style of communication with its own norms and customs. In fact, some autistic advocates even capitalize the word “Autistic” when describing themselves to emphasize the notion of Autistic as a culture and identity, not a disorder.

The Autistic Self Advocacy Network (ASAN) is just one example of many organizations led by and for autistic people that advocate for increased acceptance and accommodation of autistic individuals. ASAN states on their website that their organization “promotes social acceptance of neurological difference as part of the broad landscape of human diversity and

seeks to bring about a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens. Acceptance of difference is essential to understanding, accomodating, and benefiting from the contributions of everyone in our society, thus allowing all people to live up to their potential” [4]. While ASAN does not advocate in favor of treatments that aim to make individuals less autistic and more neurotypical or neuroconforming, the organization does advocate for services that accommodate autistic individuals’ unique needs such as facilitated communication and occupational therapy, as well as therapy and support groups that assist autistic individuals in coping with the harmful effects of discrimination and bigotry.

In speaking about her own identity and culture, neurodivergent activist Christa Mullis shares some of the positive aspects of her experiences as an autistic person: “Something important to me is a greater sense of self-awareness. Ironically, people think we [autistic people] lack that. But ‘neurotypical’ people have no reason to have to think about how their brain works, to intimately explore how and why they react to things a certain way, why something makes them uncomfortable, why they like or dislike certain things, etc. And while it’s awful that the world isn’t already built for us, I think I’ve also come to a better understanding of who I am by having to build a more accomodating world for myself, in what adaptive equipment I use or how I communicate with others. I know who I am and what I need because I have to” [24].

Multiplicity: Divergence, Not Disorder

Another community that often views their identities and experiences through a lens of cultural and neurological difference, rather than disorder or deficit, is the community of multiple or plural systems. Being a multiple or plural system, or system for short, means existing as multiple people in one body. Although this way of being is commonly diagnosed as dissociative identity disorder, the neurodiversity and Mad Pride paradigms hold that there is nothing inherently disor-

dered or pathological about existing as multiple people. Just as it is perfectly valid and healthy for an individual born in a male body to identify as a woman, it is also valid and healthy for multiple individuals who exist in a singular body to identify as more than one person.

There exist many variations within the community of multiple systems on how each system conceptualizes their experience and identification of systemhood. For example, some systems identify as having been born as one person and experiencing the emergence of other members of the system as a result of trauma or other factors, while other systems identify as having been born as a multiple system. Some systems conceptualize members as fictional characters, aliens, or other types of beings. Regardless of each system's origin story or members' individual characteristics, many advocates agree that multiplicity is an important form of diversity that should not be cured or treated.

In a blog for the critical psychiatry web magazine *Mad in America*, neurodiversity activists Missy and Skylar Freels, who exist as a multiple system, wrote, "We're not dysfunctional or bad just because there are two of us in here. What's more important than being a socially acceptable single person is that we know how to get along and manage our trauma and our life together. Knowing this, we now strive to advocate for other systems and reach out to those that may not understand systems, to show that existing as we do is okay and that we can learn to navigate the world by cooperating. We don't need the psychiatric system or its labels to allow us to exist, or to try to fix us. We just need to be accepted as we are" [17].

Many systems view their multiplicity as a similarly positive experience. Pride, a plural activist of the system Nu Upsilon Xi, lists a variety of positive aspects that have come with the system's plurality. For her, being a member of a plural system has led to a greater understanding of inter- and intrapersonal dynamics, a profound sense of insight and awareness, and heightened empathy. She says that members of her system are "able to draw on each other's strengths to complete necessary

tasks we otherwise would not, or could not do” and that existing as a system has created a more stable and solid sense of identity for each member [2].

A Mad Pride/Neurodiversity Approach to Suicide

As stated previously in this chapter, the Mad Pride and neurodiversity paradigms acknowledge that life is difficult for everyone and recognize all reactions to life’s hardships and traumas as valid. In these paradigms, desiring to die is a natural and rational reaction to experiencing violence, oppression, exclusion, abuse, and life hardships including death, loss, illness, breakups, divorce, and unemployment. Suicidal ideation, therefore, is not a sign that an individual is thinking irrationally and needs mental health treatment. Rather, it is a sign that a person’s life circumstances have become unbearably painful. It is a sign that whatever circumstances have driven such a person to experience suicidal thoughts are, for them, worse than death.

David Foster Wallace [36] once wrote the following about suicide: “The so-called ‘psychotically depressed’ person who tries to kill herself doesn’t do so out of quote ‘hopelessness’ or any abstract conviction that life’s assets and debits do not square. And surely not because death seems suddenly appealing. The person in whom Its invisible agony reaches a certain unendurable level will kill herself the same way a trapped person will eventually jump from the window of a burning high-rise. Make no mistake about people who leap from burning windows.”

“The terror of falling from a great height is still just as great as it would be for you or me standing speculatively at the same window just checking out the view, i.e. the fear of falling remains a constant. The variable here is the other terror, the fire’s flames: when the flames get close enough, falling to death becomes the slightly less terrible of two terrors. It’s not desiring the fall; it’s terror of the flames. And yet nobody down on the sidewalk, looking up and yelling ‘Don’t!’ and

‘Hang on!’, can understand the jump. Not really. You’d have to have personally been trapped and felt flames to really understand a terror way beyond falling.”

In the case of a person about to jump out the window of a burning building, it would be absurd to shut the window and celebrate having “prevented suicide” without making some attempt to put out the flames; the Mad Pride and neurodiversity paradigms posit that it is absurd to focus on the goal of “treating suicidal ideation” or “restoring sanity to a suicidal person” without addressing the cruelty and hardships in our world that drive people’s desire to escape.

The Mad Pride movement and neurodiversity field pay close attention to all of the subtle and overt forms of prejudice and oppression that neurodivergent people and people diagnosed with mental illness experience. For many neurodivergent people, being constantly stereotyped as violent, perceived as weird or sick, discriminated against in hiring and housing processes, excluded socially, subjected to forced psychiatric drugging, or confined against their will are just some of the consequences they have faced merely for expressing who they are. Many neurodivergent people also experience or have experienced other intersecting forms of oppression such as economic inequality, sex- or gender-based violence such as sexual assault, institutional racism, and sizeism and lookism. This is their reality. And for many people, this reality feels like a burning building from which desiring to escape makes complete logical sense. Mad Pride and neurodiversity advocates often believe that suicide prevention efforts should focus on systemic and cultural change rather than individual treatment programs.

Of course, sometimes suicidal ideation may result from factors independent of systemic oppression or social issues. For example, severe chronic pain is commonly associated with suicidal ideation. Sometimes individuals may not even wish to die due to any unbearable pain or suffering at all; for example, some have reported wanting to kill themselves as a means to reclaiming control over their deaths instead of suc-

cumbing to unpredictable or involuntary ends. Like other traits and characteristics categorized as “mental illness,” the desire to die should not be seen exclusively as a sign of incompetence or pathology but rather viewed as rational and justified. At the heart of the Mad Pride and neurodiversity movements lies the notion that individuals’ decisions about their own bodies, minds, and lives should be respected.

The Social Model of Disability

It is not the intention of the Mad Pride movement or neurodiversity field to suggest that the experiences constructed as madness, mental illness, or neurodivergence do not come with suffering or limitations. Taking pride in one’s “madness” or neurodivergence is not the same as claiming that these characteristics are solely positive. In fact, the Mad Pride movement and neurodiversity field both advocate for societal acceptance of limitations.

Both the Mad Pride movement and neurodiversity field are aligned with the social model of disability. The social model of disability posits that individuals are disabled by societal barriers to access and exclusion rather than by medical conditions. For example, many deaf advocates have expressed that while their ability to hear is indeed limited, deafness would not be disabling or problematic if every deaf individual had access to sign language interpretation, closed captioning, and other accommodations. Similarly, most wheelchair users indeed have limitations on their ability to walk, but this would not be disabling or problematic (or at least significantly less disabling and problematic) if every building were wheelchair accessible and every environment accommodating to wheelchair users. For this reason, many disability activists refer to themselves as “disabled people” rather than “people with disabilities” to convey that disability is something that actively happens to people as a result of systemic injustices, rather than medical conditions or physical differences.

Disabled advocates often recognize that every individual has limitations and is accommodated in some way. For example, most people in contemporary society cannot grow their own food or build their own shelter; they rely on others to do this for them. Additionally, most people in the USA are reliant on their employers for their income and benefits, including health insurance and retirement. We consider it normal to rely on external sources for these needs; why should needing other types of accommodations be considered pathological?

There is no denying that many autistic people do experience difficulty with executive functioning such as limitations in memory, attention, and time management. Many people who experience extreme states may be limited in their ability to perform self-care tasks and activities of daily living while in those states. Many people who feel suicidal or depressed are limited in their ability to get out of bed and work at full-time jobs. But according to the social model of disability, these limitations are only problematic because individuals are not accommodated. Instead of focusing on curing or eradicating these limitations, the social model proposes solutions that provide accommodations, such as personal care attendants, work schedule flexibility or the ability to work from home, and/or disability payments to relieve individuals from work responsibilities.

Sometimes, accommodations can even include having access to different types of drugs and substances that reduce physical or emotional pain and improve individual functioning. Just as almost everyone has used coffee or some other caffeinated beverage to be more alert, some neurodivergent people may wish to use mind-altering drugs to improve daily functioning. Just as the limitation of needing to drink coffee every morning to function at one's best is not pathologized, the limitation of needing psychotropic drugs to function at one's best should not be pathologized. Neurodiversity and Mad Pride advocates do maintain, however, that all individuals deserve the right to informed consent about whatever substances (or other accommodations) they choose to use, and accommodations should never be forced upon anyone.

Disability rights activist Cal Montgomery speaks of the importance of providing a model in which the strengths and limitations of neurodivergent identities can coexist: “We talk a lot about traits people – ourselves and others – have that we don’t like, but we never seem to investigate how they are connected to traits we value. For instance, I know people who don’t always show up when you want them to, and if you follow the threads, this seems largely connected to what we call depression and anxiety.”

“And, fair enough, it would be nice if they came to things when I wanted them to, so there is a temptation to think I would be happier if they had less of those issues. But, those same traits are also connected to some of my favorite things about them. Anxiety often seems to be related to a deep concern with behaving ethically. Depression often seems connected to empathy. Not always. But often.”

So then when I evaluate how personally annoying I may find it that So-and-So wasn’t at Event, I start asking myself, do I care enough about what a profoundly kind and considerate person So-and-So is to gladly accommodate that sometimes they can’t be there? The answer is usually yes. [23]

Why Mad Pride and Neurodiversity Are Incompatible with Coercion

Central to the frameworks of Mad Pride and neurodiversity is the idea that distress and difference should be accepted. Sometimes the characteristics that are categorized as mental illness are embraced and celebrated. Other times, celebration is not called for, such as when these characteristics cause suffering or result from trauma. However, even in these latter instances, they can be accepted as valuable and rational. The Mad Pride and neurodiversity paradigms propose that under no circumstances should people be punished for their differences or distress.

Numerous accounts from people with lived experience speak to the traumatic and harmful nature of involuntary com-

mitment, forced drugging, and forced electroshock treatment [7, 8, 13, 16, 19, 23, 26, 27, 33]. Many people who identify as “psychiatric survivors” have spoken out about the violent nature of having these acts forced on them. The author, a victim of involuntary commitment and forced treatment, has contributed several such accounts [10–12, 30, 31]. Underlying the principles of Mad Pride and neurodiversity is the notion of Mad and neurodivergent autonomy: people should be considered the experts and sole proprietors of their own minds and bodies; no matter how much distress individuals are in and how different they are from what is considered “normal,” they still deserve the right to make decisions about their own brains and bodies.

One conceptual framework that is closely related to Mad Pride and neurodiversity is the notion of cognitive liberty. Cognitive liberty advocates support the right of each individual to experience any and every thought, feeling, belief, state, and expression of such as long as it does not violate another person’s bodily autonomy. Another way of saying this is that cognitive liberty activists support the right of all people to alter their minds and consciousness however they choose (including the decision to cease being conscious) and not have their consciousness altered against their will. Cognitive liberty encompasses the right to experience “madness” and be neurodivergent; it also encompasses the right to use mind-altering drugs.

Many psychiatrists, including some who identify as critical psychiatrists and have contributed to this book, argue that coercion may be justified for individuals in instances in which all nonrestrictive alternatives have been attempted and they appear to be at legitimate risk of harming themselves or others. While Mad Pride and neurodiversity activists recognize this as an improvement upon current practices of coercion in mental healthcare, the movements tend to support abolitionist, not reformist, stances on coercion. They believe that individuals should retain full autonomy over their bodies, even if this results in death or bodily injury; the choice to value liberty and autonomy over life should be a choice an individual – regardless of mental state – has the right to make.

As a Mad Pride and neurodiversity activist and a survivor of forced psychiatric treatment, I am not fully safe from psychiatric coercion unless all of us – all Mad and neurodivergent people, people labeled “mentally ill,” and all people in general – are safe from psychiatric coercion. Just a few members of this group being subjected to this kind of violence has an effect on the entire community; not only do community members experience the vicarious trauma of their friends’ and comrades’ loss of autonomy, but they also experience the fear that if they reach a certain degree of perceived madness or departure from societal norms, they, too, may lose their liberty. Although I remain free from force and coercion, I am not free from its threat – and I am certainly not free from witnessing the pain of my friends and comrades whose autonomy continues to be violated.

At the same time, I have also experienced the pain and trauma of losing a friend and comrade to suicide, and I can empathize with the instinct to prevent suicide at all costs. I do not minimize the pain resulting from the death of any loved one. However, the Mad Pride and neurodiversity communities privilege the values of liberty and personal autonomy; to experience a loved one’s loss of liberty can also involve a process of mourning and pain.

Chapter 7 of this volume, “Coercion and the Critical Psychiatrist,” places emphasis on conversing with clients in a transparent way when discussing coercive practices. While increased honesty about the intentions of these practices is certainly an improvement, countless survivors of psychiatric coercion would argue that no words or language can take away the violent and traumatic nature of this act. I was forced to miss my college graduation due to being involuntarily committed; even having been committed by a compassionate and transparent psychiatrist would not have made up for the fact that I was forced to be absent at a milestone event I had spent years working arduously to achieve. While I was hospitalized for passive suicidal thoughts, my ideation became active as soon as I experienced the intensity of the regret, guilt, and shame resulting from being excluded from this occasion.

But What if Someone Gets Hurt?

As mentioned earlier in this chapter, people diagnosed with mental illness are far more likely to be victims of violent crimes than perpetrators. However, there are instances in which the experiences categorized as madness can lead to violence toward others. For example, people may hear voices or experience hallucinations telling them to harm others.

Many Mad Pride and neurodiversity advocates recognize that violent impulses are often shaped by systemic and contextual factors. Sometimes, individuals are driven to violent impulses and actions by being made to feel fearful and powerless; repeated victimization in the form of abuse, ostracization, or trauma can lead a person to use violence or aggression as a recourse to regain power. Many psychiatric survivors and victims of involuntary commitment report becoming more aggressive after being confined or forcibly drugged, as these acts led to intense fear and panic. In the Mad Pride and neurodiversity paradigms, it is important to recognize the factors in people's lives that may contribute to their thoughts of harming others. In this way, we can humanize those whose actions seem irrational and incomprehensible at first glance. Sometimes, the recognition that violent impulses are coming from feelings of powerlessness and abuse along with working to address ways to change a person's circumstances is enough to prevent violence and resolve any potentially dangerous situation.

This does not mean, however, that society should be unprotected from actions that put them in danger by violating their bodily autonomy. The majority of Mad Pride and neurodiversity advocates believe that detention or confinement is called for when a person has made an active threat to harm others. However, Mad Pride and neurodiversity advocates would maintain that such confinement or detention should not be dependent on an individual's neurodivergence or psychiatric diagnosis. Instead, we should seek to protect society from potentially violent acts in the most humane, compassionate way possible that considers the contextual

and systemic circumstances surrounding the threat or act of violence that has occurred. Many Mad Pride and neurodiversity advocates support the development of alternative methods for addressing violence besides the criminal justice or psychiatric systems. The proposed alternatives often focus on addressing systemic inequality and injustice rather than attributing violence to an inherent characteristic within an individual such as criminality or mental illness.

Going Forward

Although the Mad Pride and neurodiversity movements represent a radical shift from the dominant paradigm of psychiatry and mental healthcare, these movements are not irreconcilable with the practice of psychiatry. As mentioned previously in this chapter, psychiatrists and mental health professionals once pathologized queer identities and practiced forms of conversion therapy; now, many psychiatrists and mental health professionals practice LGBTQ-affirming therapy, respect their clients' queer identities, and validate the trauma of experiencing queer antagonism. In the same way, it is possible to practice psychiatry and psychotherapy that is affirming of madness, neurodivergence, and all of the traits and phenomena categorized as "mental illness."

Such a practice could include introducing clients to paradigms like Mad Pride and neurodiversity and assisting clients in deciding what traits they want to change or alter and what traits they would prefer to accept and embrace as part of their identities. Psychiatrists and mental health professionals could help clients explore the positive or valuable aspects of these characteristics and support clients in developing greater self-acceptance. Therapy may also include an exploration of how clients' particular traits or phenomena may represent valid responses to systemic issues or external circumstances and how they may be helpful, not harmful, coping mechanisms.

One major role that a psychiatrist or therapist can play in affirming, rather than pathologizing, a client's identity can be

determining what kinds of changes could be made to the client's external environment in order for the client to feel more accepted and included on a day-to-day basis. For example, many young neurodivergent clients may face family rejection or peer victimization; they may be bullied by their classmates due to being perceived as different or seen as burdensome by their parents. Psychiatrists and mental health professionals can help young clients' families and schools shift their negative attitudes toward neurodivergent youth by providing educational information about the importance of inclusion and the traumatic impact of exclusion or sanism, i.e., prejudice or discrimination on the basis of a person's mental or emotional characteristics. Psychiatrists and mental health professionals can also advocate for their clients to receive accommodations from their workplaces, schools, or housing or assist their clients in finding support groups or other social settings that are inclusive toward people with their particular characteristics.

Another way psychiatrists and mental health professionals can practice this "mad-affirming" or "neurodiversity-affirming" care is by validating the trauma of the discrimination and prejudice clients face on account of their "madness" or neurodivergence. Too often, clients are blamed for the prejudice and exclusion they experience. They are told that they should act more "normal" and "healthy" in order to not be victimized. Additionally, they are often told that they should be grateful for having been involuntarily committed or forcibly treated or that they should forgive the well-intentioned people who carried this out against them. Critical psychiatrists and mental health professionals can instead recognize the real, tangible effect of involuntary commitment and sanism on the brain and body and assist clients in healing from, coping with, or addressing this trauma in whatever way they choose.

Underlying "madness-" and "neurodiversity-affirming" mental healthcare would be the principle that clients reserve the right to their own conceptualizations and interpretations of their experiences, traits, characteristics, and phenomena. Their voices, experiences, and wishes regarding their minds, bodies, identities, and course of care would be respected above all.

Clients would always be presumed to be competent to make their own decisions, including the decision as to whether a particular trait or internal experience (including suicidality and self-harm) should be celebrated, embraced, accepted, managed, treated, cured, or some combination of all of the above. This form of mental healthcare would involve a collaborative, non-authoritative relationship – an equal partnership between psychiatrist and client that is free from coercion.

While it is unlikely that coercion can immediately be eliminated from the practice of psychiatric care, one way to reconcile current legal requirements with practicing “mad-affirming” and “neurodiversity-affirming” care could be to be as open and honest with clients as possible about when commitment or other reporting would become necessary. This gives clients the option to choose not to disclose any information that might result in involuntary commitment or forced treatment.

Psychiatrists and mental health professionals can also choose to support the principles of Mad Pride and neurodiversity outside of the therapy room. They can speak out about these ideas in both informal and academic writing as well as introduce these ideas to their colleagues, students, and professional organizations they may belong to. They can always look for ways to center the voices and perspectives of people with lived experience in their research, writing, and speaking.

As a final note, attention should be paid to the privilege and power afforded to psychiatrists and mental health professionals. Within society and the healthcare system, they are assumed to be the experts on the cognitive and emotional characteristics categorized as “mental illness.” This idea does not apply to any other marginalized group: white race studies scholars are not assumed to be the experts on what it is like to be a person of color, and straight queer studies scholars are not given the authority to define and theorize the queer experience. Yet psychiatrists and mental health professionals carry significantly more credibility and weight when speaking about “mental illness” than do people who have been diagnosed with mental illness, who are often discredited and dismissed as “crazy” or “irrational.”

Until this changes, psychiatrists and mental health professionals have tremendous power and authority to legitimize and validate the perspectives of people with lived experience, such as neurodiversity and Mad Pride. They have the ability to be taken seriously when introducing these ideas into the conversation, and that ability should be considered heavily. It is imperative that, going forward, critical psychiatrists closely examine how they can use the power they have to elevate and center the voices of those who are taken less seriously due to being perceived as mentally ill, pathological, or incompetent. In this way, critical psychiatrists and mental health professionals can add a great deal to the Mad Pride and neurodiversity movements by striving to bring rights-based, madness-affirming, context-informed care into a field that has historically been paternalistic and oppressive.

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