MENTAL DIVERSITY AND MEANINGFUL PSYCHIATRIC DISABILITIES

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ABSTRACT

This dissertation provides a philosophical investigation of key claims arising from the psychiatric user/survivor movement. Users/survivors insist that psychiatric conditions do not necessarily diminish someone’s agency or ability to flourish; rather, they argue that they can find meaningful agential opportunities in virtue of their psychiatric disability. They believe that their form of difference—mental diversity—deserves institutional and interpersonal recognition. This movement therefore challenges standard ways of conceptualizing mental illness, duties of recognition, and what constitutes a valued mode of being. All of these challenges have implications for health care professionals’ ethical obligations and responsibilities in relation to this patient population. I argue that many of the insights from the disability rights movement can help illuminate the philosophical underpinnings of the psychiatric user/survivor movement, though there are differences in the specific normative demands of these two movements. Similar to how the disability rights movement disputes able-bodied norms, user/survivor activism rejects able-minded or “sanist” norms. The movements are not precisely parallel, however, given the distinctive features of psychiatric disabilities.

My focus is on value-laden conceptions of mental illness, preemptive paternalism and conflicting claims to epistemic authority, and the tension between respecting “generative madness” on the one hand and avoiding neglect or abandonment of individuals in need on the other. I show that disability modeling accommodates many of the claims from users/survivors,
including the claim that their disability can be a source of value that deserves recognition. I argue that their demands for recognition of mental diversity will encounter significant obstacles, but those obstacles are not insuperable for all of those represented by user/survivor activism. I illustrate how a psychiatrically disabled mode of being can be cared about because it is meaningful, which leads to *prima facie* obligations that should shape the clinical encounter. The therapeutic relationship provides a critical opportunity for interpersonal recognition. I argue that shared decision-making can be possible when recovery goals accommodate, within limits, modes of being that the patient cares about in virtue of being meaningful.
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INTRODUCTION

This dissertation provides a philosophical investigation of key claims arising from a social justice movement that has received relatively little attention from philosophers and bioethicists, though it has existed for almost fifty years: the psychiatric user/survivor movement. This movement has its roots in narratives from patients who challenge dominant understandings of what it means to live with the diagnosis of mental illness. The psychiatric user/survivor movement (also referred to as the consumer/survivor/ex-patient movement\(^1\)) began in the 1970s, taking inspiration from other civil rights groups of the time. By adopting the title of *survivor*, these individuals show their rejection of “forms of professionally led and produced information.”\(^2\) The groups are mainly comprised of self-described radical mental health professionals and people diagnosed with mental illness who have experienced the mental health system in some form. Although its philosophical roots are in anti-psychiatry, the user/survivor movement has evolved over the years, becoming more nuanced as it has branched throughout the world. Prominent groups today include MindFreedom International, the Icarus Project, INTERVOICE Hearing Voices Network, and the National Paranoia Network.

From their mission statements, campaigns, literature, and narratives, I have discerned several important philosophical claims in this movement. Users/survivors insist that psychiatric

\(^1\) Some activists believe that ‘patient’ suggests a passive sick role, so they reject it; others prefer the term ‘consumer’ to ‘survivor’ because the latter implies traumatic experience which might be an over-exaggeration in some cases. Still other activists think ‘consumer’ is a less-than-ideal label because consumers are thought to buy into the pharmaceutical industry or to be dependent on Supplemental Security Income and the like (Morrison 127). I use the term ‘user/survivor’ to note their past history (use) with the mental health system and their radical rejection of some of the practices and assumptions fundamental to current psychiatric care (survivor). When I refer to them as current and past patients, I do not mean to imply that they are passive recipients of care. Rather, the term ‘patient’ is helpful for separating the roles of medical professionals and those who are being cared for—though they might be partners in care.

\(^2\) Tait & Lester 169
conditions do not necessarily diminish someone’s agency or ability to flourish; rather, they argue that they can find meaningful agential opportunities *in virtue of* their psychiatric disability. They believe that their form of difference—mental diversity—deserves institutional and interpersonal recognition. Users/survivors want to empower individuals with psychiatric disabilities who value their disabled modes of being, and they want health care professionals, policy makers, and others in society to respect their self-defined identities and interests. Users/survivors reject pressures to adopt conventional modes of being that fit mental health norms and are more socially accepted. When someone claims that she values her psychiatric disability and wants it respected as a form of human difference, these claims are often met with skepticism and paternalism. Achieving recognition for users/survivors will have distinctive philosophical challenges, since their claimed identities are perceived as dangerous, risky, or otherwise in need of medical management.

The user/survivor movement challenges standard ways of conceptualizing mental illness, duties of recognition, and what constitutes a valued mode of being. All of these challenges have implications for health care professionals’ ethical obligations and responsibilities in relation to this patient population. Users/survivors champion the notion of “generative madness,” according to which “psychic difference is something to value, to be proud of, to channel, and even to enhance.” The very notion of “generative madness” is incoherent according to standard interpretations of mental illness. To get started, I argue that many of the insights from the

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3 Lewis 145. ‘Madness’ in this context is supposed to function as a reclaimed term; although historically “the mad” were locked away and viewed as unruly threats to civilized society, in this movement ‘madness’ denotes a special mode of being that defies conventional notions of normality and health. Lewis explains that “‘madness’ facilitates a connection between academic critiques and mad pride activists, artists, and intellectuals who have followed in the footsteps of black pride and gay pride to destabilize and reverse the binaries and hierarchies associated with mainstream psychiatry” (ibid.). I will not use the terms ‘madness’ or ‘the mad’ in my own analysis, since it is debatable to what extent this reclamation project has been successful.
disability rights movement can help illuminate the philosophical underpinnings of the psychiatric user/survivor movement. Similar to how the disability rights movement disputes able-bodied norms, user/survivor activism rejects able-minded or “sanist” norms. Activists in both groups show the ways in which these norms lead to overly narrow notions of what it means to be an effective agent capable of living a worthwhile existence. The movements are not precisely parallel, however, given the distinctive features of psychiatric disabilities. Psychiatric disabilities are distinctive in that they can diminish someone’s agency, epistemic standing, and capacity to value. As such, there will be differences in the specific normative demands of these two movements.

In providing a philosophical analysis of psychiatric user/survivor activism, there are numerous puzzles and tensions that could be discussed. Their narratives challenge standard philosophical views on a number of topics, and this dissertation is by no means a comprehensive examination of all the intricate ideas put forward by this movement. My focus is on value-laden conceptions of mental illness, preemptive paternalism and conflicting claims to epistemic authority, and the tension between respecting “generative madness” on the one hand and avoiding neglect or abandonment of individuals in need on the other.

I show that disability modeling accommodates many of the claims from users/survivors, including the claim that their disability can be a source of value that deserves recognition. I argue that their demands for recognition of mental diversity will encounter significant obstacles, but those obstacles are not insuperable for all of those represented by user/survivor activism. I contend that mental diversity ought to be recognized as a valuable form of difference, even though the duties of recognition will be fine-grained and limited in some cases. I illustrate how a
psychiatrically disabled mode of being can be cared about because it is meaningful, which leads to *prima facie* obligations that should shape the clinical encounter. Especially given the acute vulnerability that individuals with psychiatric disabilities often experience in clinical contexts, the therapeutic relationship provides a critical opportunity for interpersonal recognition. As an approach to the therapeutic relationship, shared decision-making is meant to grant participatory parity to both the health care professional and the patient. I argue that through the shared decision-making process, which can be possible even in difficult cases, the health care professional and patient could discover recovery goals that accommodate, within limits, modes of being that the patient cares about in virtue of being meaningful.

In the first chapter, I give background on the user/survivor movement and provide an overview of some of the prominent groups active today. I identify key harms that these activists believe former and current mental health patients experience due to their psychiatric diagnosis, and I analyze the unifying aims of user/survivor activism. Next, I connect the disability rights movement to the psychiatric user/survivor movement, highlighting their philosophical parallels. I demonstrate that these movements will nevertheless diverge philosophically and politically, which starts to build the case that users/survivors will have distinctive challenges in trying to achieve their aims. I outline the central philosophical puzzles that guide this dissertation, all of which are interrelated.

In chapter two, I argue that mental illness should be conceptualized using disability modeling, and I propose my own model for psychiatric disability. The disability models under discussion come out of the interdisciplinary field of disability studies, and they prioritize first-person reports of living with disability. These models provide a framework for interpreting the
experience of disability, and they critically assess underlying normative assumptions behind dominant interpretations of disability. I argue that in addition to providing causal explanations and identifying who qualifies as having a disability, these models also have an evaluative function in suggesting what the impact of disability is for someone’s flourishing potential. I describe the types of biomedical and social models that are prevalent in the existing literature. As a type of disability, psychiatric conditions pose their own challenges for modeling. I analyze these challenges and argue for interactionist modeling of psychiatric disability. Interactionist modeling avoids reductionistic or overly simplistic explanatory stories for psychiatric disability. Interactionist models are dynamic and contextual, and they focus on the relationship among variables that all contribute to the existence and experience of disability. An interactionist model does not presume from the outset that any particular individual with a psychiatric disability is right or wrong in her report about her flourishing potential. An interactionist model does leave conceptual room for the possibility that someone could flourish in virtue of her disability; such a claim is not unintelligible on this model.

I argue in chapter three that users/survivors’ demands for recognition are in the same vein as those of other social justice movements. I outline the philosophical foundations of recognition politics as they pertain to public and private spheres. The public sphere incorporates laws, polices, and institutional structures. The private sphere is made up of interpersonal interactions, such as those that occur in intimate relationships and encounters with health care professionals. In order to clarify what recognition could mean for mental diversity as argued by users/survivors, I analyze what it means for other movements, including those for cultural, ethnic, and racial minorities; the disability rights movement; Deaf Gain; and neurodiversity. Users/survivors’
demands for recognition have special obstacles to overcome, given how their valued identities are pathologized. Additionally, users/survivors’ epistemic standing to make recognition claims is often doubted. I analyze their first-person counterstories and contend that the obstacles to achieving recognition are not insurmountable.

Chapter four delves more deeply into the central claim of users/survivors: that they value their mental diversity, and they want their disabled mode of being to receive recognition as another form of human difference. I argue that when a mode of being is cared about because it is meaningful, there are prima facie obligations to respect it as a central moral interest. I provide a conception of mode of being, and I discuss some of the different ways in which it can be valued by an agent. I build on Agnieszka Jaworska’s account of caring and Cheshire Calhoun’s account of meaningful living. When a mode of being is cared about because the agent finds meaning in it, I call it a pleroma, borrowing from the ancient Greek term for that which fills or is fulfilling. I contend that pleroma represent moral interests that are central to an individual’s sense of self and agency over time. Mental diversity consists of pleroma associated with psychiatric disability. I argue for prima facie obligations that mental health professionals have in relation to psychiatrically disabled pleroma in clinical contexts. When these obligations are fulfilled, patients with psychiatric disabilities can achieve interpersonal recognition of their mental diversity in the clinical encounter.

The fifth and final chapter gives an in-depth philosophical analysis of shared decision-making in mental health contexts. I argue that this approach to the therapeutic relationship opens the door for interpersonal recognition by supporting patients’ agency and values in decision-making. I focus on difficult cases where shared decision-making seems unachievable in virtue of
a) doubts about the patient’s epistemic standing and b) deep disagreements about what the therapeutic goals ought to be. I start the chapter by providing an overview of different models of the therapeutic relationship, and I reject paternalistic and consumer-driven models. I defend a robust conception of shared decision-making, and I critique how this model is portrayed in the current literature. Although leading organizations and user/survivor groups champion shared decision-making in mental health contexts, the impediments for achieving it have not been adequately addressed. I develop recommendations for how to achieve shared decision-making in difficult cases, showing how this model can be successful when patients’ insight evaluations have less weight and there is a more holistic interpretation of what it means to “get better” with psychiatric disability.
CHAPTER ONE: DISTINCTIVE AIMS AND CHALLENGES OF PSYCHIATRIC USER/SURVIVOR ACTIVISM

Psychiatric users/survivors report on various forms of abuse and neglect that they have experienced in the mental health system and larger society as a result of their diagnosis. The abuse and neglect can reveal itself in individual attitudes as well as institutionally in many spheres of life. Their mistreatment, in their eyes, is not a matter of isolated incidents from maliciously minded individuals. They reveal that stigmas and misperceptions about mental illness can unfairly jeopardize their perceived epistemic standing, which has long-ranging implications. One implication is that individuals with a psychiatric history are often subjected to a stance of preemptive paternalism in many of their interactions, inside the clinic and elsewhere. This stance leads others to doubt their claimed epistemic privilege regarding their own condition, at least when their purported knowledge conflicts with the dominant biomedical understanding of mental illness.

Mental illnesses are heterogenous and lie on an enormous spectrum; whereas some of these individuals will rarely need medical assistance, others will be routinely engaged with mental health professionals and reliant on community resources for their everyday living. For patients who experience medical interventions and even potential hospitalizations as a regular part of life, they will be largely dependent on others for what services they receive and how those services are provided. This dependency on assistance can feed into these patients’ sense of being marginalized, given how health care professionals, caregivers, policy makers, administrators at shelters, and others will effectively determine how these patients live their lives. As put by Iris Marion Young:
the old, the poor, and the mentally or physically disabled are subject to patronizing, punitive, demeaning, and arbitrary treatment by the policies and people associated with welfare bureaucracies. Being dependent in our society implies being legitimately subject to the often arbitrary and invasive authority of social service providers and other public and private administrators, who enforce rules with which the marginalized must comply, and otherwise exercise power over the conditions of their lives. [...] Dependency in our society thus implies, as it has in all liberal societies, a sufficient warrant to suspend basic rights to privacy, respect, and individual choice.\textsuperscript{4}

The group of former and current psychiatric patients who identify as users/survivors contend that anyone diagnosed with a mental illness will face barriers to participation in treatment decisions and other areas of life.

To clarify the scope of this project, I will focus on how the user/survivor movement presents today after evolving through the last fifty years. My discussion relates to the context of mental health care in the United States, though it could have applicability to other countries that are similarly situated where users/survivors make similar claims. My analysis is not confined to any one clinical context; I provide a philosophical lens to patient reports and experiences from long-term psychiatric institutions, hospitals, and outpatient clinics. Since users/survivors and those they represent have diagnoses across the spectrum of mental illness, this project is not limited to any mental illness category or symptom cluster. There are many individuals with psychiatric conditions who would not identify with user/survivor activism, so this movement should not be considered to be speaking for all diagnosed individuals. I am not attempting to examine the experiences and perspectives of all individuals with psychiatric conditions. I am

\textsuperscript{4} Young, “Five Faces of Oppression” 54
narrowing my analysis to the claims put forward by contemporary users/survivors (which is also a heterogenous group).

Individuals with psychiatric disabilities regularly confront a form of clinical reductionism, which is characterized by widespread paternalism, pervasive doubts of their reports and epistemic testimony, and extreme biomedical modeling of their conditions. The user/survivor movement emphasizes patient radicalism, which prioritizes patient control and empowerment, the social dimensions of psychiatric disability, and patients’ epistemic authority. I identify and weigh competing normative considerations that underlie the tension in these positions. Both of these positions—clinical reductionism and patient radicalism—are philosophically and ethically problematic. They both represent extreme portrayals of psychiatric disability that are often without nuance. Whereas clinical reductionism can lead to an unwarranted paternalistic stance and discounting of patients’ experiences, the agenda embedded in patient radicalism could lead to neglect or abandonment and reduced access to services for those who want or need mental health support. Each chapter tackles important philosophical issues at the heart of this tension, offering a disability-conscious bioethical analysis that takes seriously key concerns coming from patients and mental health professionals.

In this chapter, I give background on the user/survivor movement, tracking how their central claims and activism have evolved over the decades. I describe some of the most prominent user/survivor groups that are currently active, along with their campaigns. I identify the key harms that users/survivors believe that individuals with psychiatric diagnoses are vulnerable to due to their diagnosis. Shared experiences of these harms have unified these individuals in their social justice movement, and I analyze the aims that underlie their activism. I
start to build the case that the user/survivor movement has many philosophical parallels with the
disability rights movement, though psychiatric disabilities are importantly distinct from other
types of disability. I close by outlining the central philosophical puzzles at the heart of this
dissertation. For one, there are looming philosophical questions in how to conceptualize mental
illness, particularly given how value-laden assumptions affect the interpretation of these
conditions. Second, there is a tension between the preemptive paternalism commonly found
within psychiatric practice and the epistemic authority claimed by users/survivors. Further, many
users/survivors embrace a notion of generative madness, according to which their psychiatric
impairment is uniquely valuable to them. If psychiatrically disabled modes of being deserve
recognition as another form of human difference, then there are significant implications for the
therapeutic relationship and therapeutic goal-setting.

BACKGROUND ON THE PSYCHIATRIC USER/SURVIVOR MOVEMENT

In the beginning stages, R. D. Laing and Thomas Szasz provided the philosophical
backbone of the activist projects. According to these antipsychiatry theorists, mental health
interventions are generally more harmful than beneficial; mental illnesses are myths that are used
for social control; and some interventions, such as electroshock therapy and involuntary
commitment, violate human rights. Judi Chamberlin’s 1979 memoir, On Our Own, became a
foundational text for the movement and further convinced many diagnosed individuals that peer-
run alternatives had the potential to be far more effective and less stigmatizing than traditional

5 The Antipsychiatry Coalition publishes some more recent writings of theorists in this vein. There are some
disagreements on when and how involuntary commitment could potentially be ethically or socially permissible.
medical therapies. Activists in the 1970s modeled their movement after other advocacy groups, such as those organized around women’s health, disability, and AIDS; they “stressed common themes of questioning medical authority, promoting self-determination, and resisting stereotypes.”

From these roots, user/survivor groups have spread around the world, and many remain active with regular gatherings and protests.

Prominent User/Survivor Groups

Thousands of users/survivors form communities around the world. Whereas some groups come together based on a shared diagnosis, others groups are created on the basis of shared experiences (such as auditory hallucinations). I will provide an overview of some of the most prominent groups today: MindFreedom International, the Icarus Project, INTERVOICE Hearing Voices Network, and the National Paranoia Network.

Mind Freedom International (MFI) is a global activist network of over 100 grassroots organizations and thousands of members. MFI’s mission statement runs as follows: "In a spirit of mutual cooperation, MindFreedom leads a nonviolent revolution of freedom, equality, truth and human rights that unites people affected by the mental health system with movements for justice everywhere." They want to empower psychiatric patients to choose their own mode of being, even if doing so is against standard medical advice. Members of MFI insist that mental illnesses do not necessarily diminish their well-being. Moreover, even if an individual does want certain symptoms treated, MFI argues that that individual should be able to determine the course and

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6 Tomes 724
7 MindFreedom.org, “Who We Are”
manner of treatment. In 2008 the former World Health Organization Mental Health Director, Benedetto Saraceno, stated:

WHO has different views from MindFreedom in some areas, such as the definition of mental disorders or mental disability, or the assessment of the advantages and disadvantages of psychotropic medicines, but WHO also shares many common views with MindFreedom concerning the right of choice about treatment and, above all, the need of addressing the global emergency about the violation of human rights.\(^8\)

MFI recently protested against bills that would permit mandatory screening for mental illness in schools and against hospital policies that permit forced electroconvulsive therapy. MFI collects testimonies from users/survivors who describe their experiences with the mental health system. Their testimonies attest to paternalistic treatment, dismissal of their values, and dehumanizing practices.

MFI has numerous ongoing projects around the world, many of which have made national news. Their Choice in Mental Health Care campaign tries to establish a variety of viable options for treatment, including those that are considered more safe and humane than standard psychotropic drugs. Activists want to “allow people’s experiences to become more important than the diagnoses, validate the person and their experience, and encourage the person to come up with their own answers.”\(^9\)

Mad Pride, another prominent campaign, has roots in the 1960s and 1970s in the mad liberation movement led by psychiatrists and patients. Members of Mad Pride strive to have their rights to self-determination acknowledged by institutions through “reclaiming

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\(^9\) MindFreedom.org, “Choice in Mental Health Care Campaign Committee”
the experience of madness and the language surrounding it.”\textsuperscript{10} They hold events to celebrate their “mental diversity” and “unusual (some call them ‘spectacular’) ways of processing information and emotion.”\textsuperscript{11}

The MFI Shield Program provides assistance to registered members who are threatened, coerced, or forced into psychiatric treatment. The Solidarity Network raises awareness when a member has had her human rights violated as a result of psychiatric intervention, and they take nonviolent action to try to retrieve the individual from confinement. The I Got Better campaign “aims to challenge the dominant narrative of hopelessness in mental health care by making stories of hope and mental wellness widely available through a variety of media.”\textsuperscript{12} MFI’s Boycott Normal campaign has received some press for its protests against psychiatric corporations and the American Psychiatric Association. In response to the rewriting of the \textit{Diagnostic and Statistical Manual of Mental Disorders}, MFI activists held an Occupy the APA event during which they marched to the doors of an APA meeting and ripped words like ‘depressive’ and ‘sick’ and diagnostic labels.\textsuperscript{13} In the United States, members of MFI also objected to the appointment of Sally Satel to the advisory council at the Center for Mental Health Services. Satel describes Mad Pride as the “‘guinea pig rebellion’.”\textsuperscript{14}

The Icarus Project, another psychiatric user/survivor group, began in 2002 and has over 8,000 members. These advocates view mental illness as “dangerous gifts needing cultivation and

\footnotesize{\textsuperscript{10} Mad Pride 7  
\textsuperscript{11} Quart n.pg.  
\textsuperscript{12} IGotBetter.org  
\textsuperscript{13} MindFreedom.org, “Boycott Normal”  
\textsuperscript{14} Qtd. in Lewis 170}
care, rather than diseases or disorders” and “extreme states of consciousness.” William Hall, who has schizophrenia and advocates on behalf of Icarus, testifies to the positive aspects of mental illness that can be overlooked by mental health professionals. Hall argues that diagnosed individuals can “transport what are often considered simply horrible diseases into an ecstatic, creative, productive or broadly ‘spiritual’ condition”. Icarus activists explicitly reject the medical model and “challenge standard definitions of psychiatric difference as essentially diseased, disordered, broken, faulty, and existing within the bounds of DSM-IV diagnosis.”

Besides building a website with resources, this group also promotes artistic expression, public awareness and education, and access to peer-run alternative treatments. According to Icarus, alternatives can promote self-care and individual goal-setting more effectively than standard treatments, and they are less stigmatized as well. Further, they promote “non-hierarchy and anti-oppression”. Icarus argues that users/survivors should have their viewpoints incorporated more thoroughly in all levels of the mental health system.

The INTERVOICE Hearing Voices Network began in 1997 with a meeting of “voice hearers” and mental health workers in Maastricht, Netherlands. ‘INTERVOICE’ stands for International Network for Training, Education, and Research into Hearing Voices. The group invites voice hearers from all psychiatric backgrounds. Among their stated aims, INTERVOICE has education campaigns and tries to increase mutual support for voice hearers across the world. They rebuke standard medical interpretations of voice hearing and urge self-definition: “Whilst it

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15 TheIcarusProject.net
16 Quart n.pg.
17 TheIcarusProject.net
18 Ibid.
is the case that some people define hearing voices as a symptom of medical illness, other voice hearers are able to live with their voices and consider them as a positive (or at least manageable) part of their lives.”¹⁹ They contend that their experiences give them unique expertise that should be part of therapeutic discussions. INTERVOICE encourages providers to see patients as equal participants: “We believe that we do not need to maintain a [health care] worker/psychiatric survivor divide.”²⁰ Treatment options should not be researched, funded, and implemented without input from those who understand the actual experience of hearing voices, they contend. They want to “show that hearing voices is a normal though unusual variation in human behaviour,” and “the problem is not hearing voices but the inability to cope with the experience.”²¹ From their standpoint, medical interventions should not necessarily target voices; rather, voice hearers need support to choose the mode of being that best suits their values.

The National Paranoia Network (NPN) was started in 2004, and it brings together individuals diagnosed with various mental illnesses who experience different levels of paranoia. They host conferences across the globe and publish newsletters and literature, including testimonies from current and past patients. The group aims to raise awareness of “how disabling paranoia can be and to break down social taboos”.²² NPN does not celebrate paranoia or dismiss its disabling effects, though they do take stigma against these individuals seriously as a significant factor in their distress. NPN has support groups that are run by people with experiences of paranoia and hearing voices (when an associated symptom), so individuals can

¹⁹ INTERVOICEOnline.org
²⁰ Ibid.
²¹ Ibid.
²² NationalParanoiaNetwork.org
find community in their struggles. A core aim is to give them “a sense of control and empowerment over paranoia beyond the scope of taking medication or self medicating” with liquor or other substances. In this way, NPN advocates for non-traditional treatment methods that do not strictly rely on the medical framing of their conditions.

**Key Harms Identified**

Users/survivors identify a number of harms that they believe individuals experience inside and outside the mental health system due to their psychiatric diagnoses. Stereotypes and stigmas feed into misperceptions about these individuals' possibilities in terms of flourishing and meaningful agency. As a group, individuals diagnosed as mentally ill routinely experience mistrust; there are rampant misperceptions about their dangerousness, unpredictability, and general competence. These misperceptions can affect daily interactions as well as public policies. If mental illness is considered a hopeless condition as a result of unchecked stereotypes, then there will be less motivation to provide adequate access to health care resources for individuals with psychiatric diagnoses who want or need these resources. As another example, since individuals diagnosed as mentally ill are commonly viewed as more dangerous, they are vulnerable to civil rights violations, questionable arrests, and other forms of violence.

Stereotypes, as Bartky explains, serve to systemically obscure reality and the active factors of oppression, so the oppressed state appears natural, given, and pathological. A 2010

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23 Rickman 17  
24 Angermeyer & Dietrich  
25 See Epperson for discussion of police violence against individuals with mental illness.  
26 Ibid 23. Bartky specifically labels this phenomenon as mystification.
study found that hope, self-esteem, empowerment, self-efficacy, overall quality of life, social support, and treatment adherence are all negatively affected when psychiatric patients internalize the stigma of mental illness.\textsuperscript{27} Jan Wallcroft recounts her burgeoning activist spirit in the light of her experiences with the mental health system and those of others like her:

although our life stories are very different, there are common threads in our experiences of having been misheard, devalued, written off and damaged because of other people’s fear of madness […] our distress and anger is often a reasonable and comprehensible response to real-life situations which have robbed us of our power and taught us helplessness.\textsuperscript{28}

Concerns about learned helplessness and internalized oppression echo throughout narratives from former and current psychiatric patients. Sandra Bartky describes ‘psychological oppression’ as being “weighed down in your mind; it is to have a harsh dominion exercised over your self-esteem.”\textsuperscript{29} Learned helplessness is connected to a sense of ineffectual agency and lost self-trust. It should be expected for patients in this situation to feel disinclined to initiate shared decision-making with mental health professionals, since this participation will not seem possible when they routinely encounter disrespect in their interactions with others.

These harms go hand-in-hand with the perception of decreased epistemic standing. Individuals with psychiatric conditions often experience doubts about their self-reports and claims to knowledge. Linda Morrison, an activist, former psychiatric patient, and scholar, states: “valuable information about [patients’] experience is only available to the professionals through patient self-report […] And yet, by the very definition of psychiatric illness, the patient’s self-

\textsuperscript{27} Livingston & Boyd 2155-2156
\textsuperscript{28} Qtd. in Crossley & Crossley 1484
\textsuperscript{29} Bartky 22
report may be considered less than reliable by the psychiatrist, particularly if self-knowledge conflicts with the physician’s view of the situation." Psychiatric patients’ general lack of recognized epistemic privilege means that others (outsiders) will determine how their condition is interpreted, what treatment options are and are not put on the table, and how recovery is conceptualized for them (if recovery is considered possible). The end result is an overwhelming sense of being marginalized in the most important aspects of their lives. Their experiential knowledge and expertise are not prioritized as they believe they should be in clinical encounters or at the level of policy.

**Unifying Activist Aims**

While some psychiatric user/survivor groups currently still reference the philosophy of antipsychiatry, the movement has branched to include groups with a variety of goals, projects, and commitments. These groups are united in advocating for more robust patient rights and reforming aspects of the mental health system that are viewed as disrespectful of or out of touch with patients’ lived experiences and needs. One of their reasons for coming together as a group is to “create an alternative space and narrative that is separate from psychiatry” and thereby “talk back” to psychiatry. “Talking back” to psychiatry for this patient movement involves wrestling some control and power away from the medical profession because, it is believed, outsider expertise has unfairly drowned out the insider expertise of patients.

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30 Morrison 4
31 Ibid. 16
I have found the following goals to be common among these advocacy groups: 1) eliminate pervasive stigmas and social, economic, and political barriers facing those diagnosed with mental illness, 2) establish the right to self-definition, 3) significantly increase the inclusion of current and past patients in policy and treatment decisions, 4) abolish psychiatric interventions that violate human rights, and 5) rethink and potentially overhaul the biomedical modeling of mental illness, allowing for accounts of flourishing in virtue of psychiatric disability. Although not all of these aims will be discussed in detail in this dissertation, I will highlight the goals that unify these international activist networks.

First, a major aim of these groups is to eliminate stigma and social barriers associated with mental illness. Long-standing biases against individuals with mental illness have resulted in increased vulnerabilities and additional social, economic, and political barriers. The National Alliance on Mental Illness reports that nearly half of homeless adults living in shelters have severe mental illness or substance use disorders.\textsuperscript{32} Data reveal widespread reports of discrimination in employment, housing, and education against individuals with psychiatric diagnoses.\textsuperscript{33} The diagnosis of mental illness can also lead to compromised legal standing. Judges and juries might be less likely to trust these individuals’ testimony and claims in court: “There are many factors at play in a legal battle, including the factual scenarios, the biases of the various individuals, and the arguments that they choose to make. The presence or absence of a psychiatric label is merely another of these factors.”\textsuperscript{34} Given the ways in which stigma,

\textsuperscript{32} NAMI, “Mental Health by the Numbers.” The causes for this are certainly multifactorial, and stigma alone does not account for the high rates of homelessness in this population.
\textsuperscript{33} Wheat et al.; Corrigan et al.
\textsuperscript{34} Emily Caplan 53
stereotypes, and biases can affect the daily life and opportunities available to individuals with psychiatric conditions, users/survivors fight to eliminate these barriers and advocate for equal standing of former and current patients.

Additionally, psychiatric users/survivors advocate for the right to self-definition:

“Reclaiming the right to define themselves and their problems is a prerequisite for attaining other objectives.”\(^{35}\) As succinctly put by one activist-scholar, “the issue of having the meaning of our experiences recognised is central.”\(^{36}\) For instance, many individuals diagnosed with mental illness report valuable symptoms (e.g., creativity) associated with their condition, not merely harmful ones. Further, they frequently attribute their distress and dysfunction to social, contingent factors rather than problems inherent to their condition. Linda Morrison states: “A thoughtful and informed recognition of their experience, more than wordplay with discrediting labels, provides an opportunity to understand, support and work with their efforts to find justice, self-determination, and non-oppressive helping alternatives.”\(^{37}\) Consulting patient experiences in the definition and interpretation of mental illness can additionally improve the physician-patient relationship by making it more participatory.

The right to self-definition is thus associated with another central aim: Increased participation and inclusion in decision-making at the level of policy and therapeutic goal-setting. Psychiatric users/survivors believe that inclusion is a necessary step to make their perspectives known—“One of the most frequent refrains amongst service users remains ‘They never

\(^{35}\) Barnes & Shardlow n.pg.
\(^{36}\) Lindow 169
\(^{37}\) Morrison n.pg.
They contend that the “physical presence of users is rarely accompanied by effective collaboration on these most fundamental issues, but instead there are a variety of ways in which their views are disregarded.” They insist that current and former patients of the mental health system should have significant roles in defining ‘mental illness,’ evaluating the quality of available services, determining worthwhile research programs, judging the fair allocation of mental health resources, and determining the funding of alternative treatment plans. Greater inclusion is needed since “users are experts about their own illness,” and “users may have different but equally important perspectives”. Users/survivors argue that including them in these decisions will help ensure that services are as effective as possible, since there is a greater likelihood that they will serve actual needs of actual patients. They argue that “treatment plans must be individualized to reflect patients’ different states of ‘readiness’ to pursue treatment”.

Another goal of user/survivor groups is to limit or abolish certain types of interventions. For example, there have been rallies and protests against forced or coerced psychotropic drug treatments, involuntary commitment, mandatory supervisions following hospital discharge, and the use of electroconvulsive therapy (ECT) under any conditions. For example, the campaign The Right to Remember works to raise awareness about problems with informed consent to ECT, and these activists suggest that ECT threatens the epistemic agency and personhood of

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38 Lindow 154-155  
39 Perkins 10  
40 Chamberlin, “User/Consumer Involvement” 12; Tait & Lester 171  
41 Tait & Lester 170  
42 Tomes 727  
43 There are disagreements among activists on some of these aims. For example, some groups only argue against forced electroconvulsive therapy. Antipsychiatry groups are skeptical of psychotropic medications generally, but other groups (e.g., MindFreedom) are supportive of patients’ right to choose this treatment.
patients by causing memory loss. As another example, activists rallied against Kendra’s Law, which allows for court-ordered assisted outpatient treatment, even when treatment is not wanted by the patient. A group of activists went so far as to set up “underground railroads” to help patients escape states where there is a standing court order for “outpatient drugging.” These types of interventions are believed to violate human rights and disrespect patients’ dignity. By having these interventions on the table, mental health professionals can dissuade some individuals with psychological distress from seeking help. Relatedly, activists want to help empower patients in therapeutic contexts, so treatment possibilities are as transparent as possible, and patients are consented with the full range of potential negative effects and options known.

Lastly, a unifying thread among these advocacy groups is a call to overhaul the biomedical modeling of mental illness. According to biomedical models, psychiatric conditions are deficits or dysfunctions that should be remedied, and mental health professionals can best treat patients with medications and therapies that address underlying biological problems. Many users/survivors instead suggest that the difficulties associated with mental illness are largely caused by labeling the behavior as abnormal and disordered. On this view, eliminating social,

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44 In 2011, the U.S. FDA’s Neurological Devices Panel met to discuss the risks of ECT. They found that anterograde memory, verbal and nonverbal, and retrograde memory, autobiographical and impersonal, are common deficits, though memories are generally recovered in this group. Nonetheless, the FDA pointed out methodological flaws in old research on this issue, especially given that patients are often subjected to multiple courses of maintenance ECT (see United States, Food and Drug Administration).

45 Kendra’s Law was enacted in New York in 1999 after a woman was pushed in front of a subway by an individual with untreated mental illness. The law is meant to protect individuals with mental illness and others if she is likely to struggle significantly in the community (based on “treatment history and present circumstances”) without outpatient treatment. The NY Office of Mental Health has more information at their website: http://www.omh.ny.gov/omhweb/Kendra_web/KHome.htm.

46 Morrison 141

47 Barnes & Shardlow n.pg.; Chamberlin, “User/Consumer Involvement” 11

48 Barnes & Shardlow n.pg.; Lindow; Chamberlin, “User/Consumer Involvement” 12.

49 See Szasz 24-25; Hacking 27; Paula Caplan; Linda Morrison. 23
political, and economic barriers will enable them to have a high quality of life; moreover, many users/survivors argue that their conditions are meaningful and worth protecting. Peer-run alternatives can empower individuals to explore the positive aspects of their condition and to find comfort in a supportive social network. Even though early psychiatric user/survivor groups objected to institutionalized psychiatry, today many of these activists accept patients and professionals who believe that there are at least some biological components to mental illness. Many of these groups are willing to admit that psychotropic medications, for example, can be a potentially reasonable treatment choice for some patients; however, they argue that these medications should not be considered the only viable option.

**Psychiatric User/Survivor Activism and the Disability Rights Movement**

This dissertation takes its cue from the disability rights movement, which has a number of similar aims as the user/survivor movement. These parallels are important to note, since a) claims and demands coming from users/survivors should be historically and philosophically contextualized, and b) many of the insights from the disability rights movement have already productively challenged standard philosophical notions about agency and a worthwhile existence. My bioethical analysis throughout this dissertation has its roots in disability scholarship. These movements should not be lumped together, however; user/survivor activism faces distinctive challenges due to the unique features of psychiatric disability in contrast with other forms of disability. I will briefly outline the major philosophical contributions of the disability rights movement, highlighting similarities with users/survivors. I will then show some of the philosophical and political tensions that exist between these movements.
**Aims of the Disability Rights Movement**

The disability rights movement (DRM) took much of its inspiration from civil rights movements in the 1960s. The DRM showed the ways in which persons with disabilities can suffer in society, even when societal attempts at helping persons with disabilities were well-intentioned (and often paternalistic). Their activism targets macro- and micro-level abuses and neglect of those within the disability community that result from pervasive ableist biases. This movement focuses on the first-person reports and lived experiences of individuals with disabilities, bringing out the ways in which discrimination and bias affect different spheres of life. The lived experience of disability can diverge significantly from dominant understandings of disability, which is evidenced in their narratives. In prioritizing the first-person reports of these individuals, the DRM rejects outsider claims to what individuals with disabilities need; the epistemic privilege lies with those who have experience with disability.

Michelle Fine and Adrienne Asch outline damaging assumptions about disability that have been critiqued by the DRM and its associated scholarship. For one, disability is assumed to be exclusively the result of biological deficits, and the biological features alone are supposed to predict what quality of life is possible. In response, activists and scholars in the DRM argue

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50 See Bryan for a historical overview of the DRM.
51 The disability community is heterogeneous, and disability activism is not monolithic. As will come up repeatedly in subsequent chapters, the type of impairment and one’s social circumstances and privileges will significantly affect which vulnerabilities and gifts are experienced. There are divisions in disability activism just like in any other social justice movement; these divisions lead to disagreements on what should be the movement’s priorities. This movement also is similar to other movements in that its members have intersectional identities, so race, gender, sexual orientation, and other facets of identity and lifestyle will shape how disability factors into one’s life.
52 Fine & Asch 332
against biomedical modeling of disability, and they show how life with impairments can be worth living and even worth protecting.53 Relatedly, it is commonly assumed that impairments are inevitably disabling, making it unlikely that anyone with an impairment could possibly flourish. The DRM emphasizes that the environment can be disabling, not the impairment itself.54 Lack of accommodations and access, discrimination, and structural prejudice regularly make it more difficult for these individuals to live good lives, but these are features of the environment, not the individual. Asch points out: “Studies of ‘quality of life’ consistently reveal that for people with disabilities, satisfaction results from achieving a harmony in their lives that can include a sense of meaning, performing expected social roles, enjoying give-and-take in their relationships, and having a sense that they live in ‘a reciprocal social world.’”55 Along the same lines, the DRM also rejects the assumption that individuals with disabilities are victims.56 Viewing these individuals as victims invites pity, infantilization, and paternalism.57 Further, it reduces their identity and casts them as helpless and hopeless. Disability scholars and activists argue that their identities can be positive and empowering, and it is not an identity to be shunned or avoided.

Additionally, many in the DRM object to the assumption that disability is totalizing for identity—that is, that disability is the defining feature of their self-concept.58 To assume that disability is totalizing is to reduce a person to her body parts. The complexity of someone’s identity should not be overlooked just because she has a disability; she should not be stripped of

53 See, e.g., work by Asch, Ho, Wendell, Shakespeare, Wasserman, Goering, and Smith.
54 Fine & Asch 332-333
55 Asch, “Describing Bioethics” 301
56 Ibid. 333
57 See ibid; Stramondo
58 Fine & Asch 334
all of the features of her identity that she values. Lastly, activists and scholars in the DRM reject the notion that disability necessarily leads to dependence or neediness. Assuming a dependent role can lead to doubts about competence, even though many individuals with disabilities can be capable of caring for themselves and caring for others. Although individuals with disabilities might need assistance with certain tasks, that does not put them in a permanent helpless state. The DRM argues that health care resources and environmental accommodations should enable the capabilities that these individuals have.

The DRM and user/survivor movement share core concerns: removing unjust institutional barriers and stigmas, pushing for wider acceptance of diverse modes of being, incorporating these individuals’ narrativedized experiences into policy and medical decisions, and expanding patients’ options and accommodations in clinical (and other) contexts. Activists in both movements argue that individuals with these conditions have their own expertise, and their human testimonies should be given significant weight. Both movements stress the importance of first-person reports and preventing unwarranted paternalistic assumptions.

**Divergence between the DRM and User/Survivor Movement**

The DRM and user/survivor activism have notable schisms, since the oppression and lived condition of physical disability and psychiatric disability are importantly separate and distinctive. As Peter Beresford points out, “There does not seem to be any clear agreement in disability discourse whether or not madness, distress and psychiatric system survivors are part of  

59 Ibid. 335
the discussion". He goes on to say that key texts in disability studies generally neglect psychiatric patients and activists; when they do mention them, it is in a “confused way which seems to accept a medicalised individual model of ‘mental illness’”—even though this modeling has been rejected as a descriptively inaccurate and politically damaging for physical disability by these same scholars.

Despite the acknowledgement from Beresford and a few others that psychiatric disability should receive more attention from disability theorists, the call has not been adequately answered. There remains hesitancy among scholars to draw out the analogies that might exist between, for example, deafness and voice hearing as conditions that could enable flourishing. Although mentioned briefly in the literature, there has not been a thorough, careful, or nuanced study of what analogies exist, what their precise limits are, or how the analogies/disanalogies should affect our philosophical understanding of these conditions or the moral requirements that accompany them. In a recent article in Disability Studies Quarterly, Nev Jones and Robyn Lewis Brown remark that “issues concerning psychiatric diversity/disorder have received significantly less theoretical and empirical attention within disability studies than topics related to physical and developmental disabilities and health.”

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60 Beresford 168
61 Ibid.
62 Some in the deaf community capitalize ‘Deafness’ to signify a cultural and linguistic identity, and they reject Deafness as a disability at all. Other deaf persons accept disability modeling of their condition.
63 For example, Scully, in Disability Bioethics, says: “Because I am chiefly concerned with how embodied, physical anomaly can affect moral perception and reasoning, I do not give much attention to nonphysical impairment or illness. Some of what I have to say, for example about social interactions, is relevant to these kinds of impairment too. However, when it comes to effects on moral judgment I think that learning disabilities and mental illness pose some distinctive questions of their own, and I have neither space nor competence to do proper justice to them here” (17).
64 Jones & Brown n.pg.
Among activists, there have been deep gulfs between those in the DRM on the one hand and those in the psychiatric user/survivor movement on the other.⁶⁵ Some DRM activists want to distance themselves from what they interpret to be overly radical claims on the part of MindFreedom International and similar groups; viewing physical disability as a social problem makes more sense, it is argued, than viewing mental disorder as a social problem.⁶⁶ In response, some MFI members have claimed that mental illness issues are different from physical disability issues because state coercion is more prevalent in the former case.⁶⁷ Some users/survivors also express concerns about accepting disability labels, since ‘disability’ is associated with suffering and pathology. Both DRM and user/survivor activists worry about being associated with the negatives of the other group.⁶⁸

Their challenges will not be completely coextensive because the specific social, economic, and political barriers that people in their community tend to face will differ. The nature of physical disability is also not identical to the nature of psychiatric disability. The accommodations needed for the former will likely be very different from the accommodations needed for the latter. Psychiatric disabilities are often episodic, and they can affect decisional capacity and agency. What someone is capable of understanding, reasoning through, appreciating, and grasping can all be affected by psychiatric disabilities. As such, someone’s psychiatric disability can justifiably lead to doubts about her epistemic standing, even though she could also be subjected to unwarranted paternalism and doubts as well. These features of

⁶⁵ See Beresford 169; Lewis 171; Jones & Brown
⁶⁶ When President George W. Bush formed the New Freedom Commission, members of the DRM and MFI temporarily formed an alliance to protest (Lewis 171). This period of unification, however, was short-lived, and schisms persist among scholars and activists.
⁶⁷ Lewis 162
⁶⁸ Beresford 169-170
psychiatric disabilities make them importantly distinct from physical disabilities, especially when it comes to accommodation and using their first-person reports for guidance. DRM activists and users/survivors commonly complain about paternalism, though paternalism could look very different for these two groups. Whereas infantilization and a pitying stance are often experienced by those with physical disabilities, fear and epistemic distancing are commonly experienced by those with psychiatric disabilities. A precise philosophical analysis of the user/survivor movement has to incorporate the distinguishing features of psychiatric disability.

PHILOSOPHICAL AND ETHICAL PUZZLES

The psychiatric user/survivor movement leads to important philosophical questions: What are the value-laden assumptions behind conceptions of mental illness? When individuals with psychiatric conditions and mental health professionals disagree on relevant values, what are the implications of conflicting claims to epistemic authority? What are the obligations (if any) to respect “generative madness,” particularly when they seemingly conflict with duties not to neglect or abandon vulnerable persons? As we will observe, there are significant disagreements regarding what individuals with psychiatric conditions are capable of and what they should value. My aim with each of these philosophical issues is to avoid the extremes of clinical reductionism or patient radicalism. As described previously, these positions err by placing too much weight on the expertise and perspective of either health professionals or patients, respectively. As long as these extreme positions are the only options, there will not be a productive way to navigate their disagreements. My hope is that this dissertation serves as a
starting point for fruitful dialogue, so the concerns of health professionals and individuals with psychiatric disabilities are properly taken into consideration with nuance and precision.

**Mental Illness as a Value-Laden Concept**

How mental illness is philosophically conceptualized will indicate which values are being prioritized over others, particularly in relation to assumptions about normalcy, health, and functioning. If mental illness is viewed as an intrinsically tragic state that necessarily causes suffering, then many claims from users/survivors will not be intelligible, such as the claim that someone can flourish *in virtue of* her psychiatric condition. Although disability models have been used for decades to discuss physical disability, they are rarely used to describe psychiatric conditions. To what extent can disability models be expanded to cover psychiatric conditions? What is gained, philosophically, if they are cast as *psychiatric disabilities*?

If disability modeling is employed, there are further philosophical questions. For one, it needs to be determined if these models can be used in the same way for psychiatric disabilities as they are for physical disabilities. Quadriplegia, deafness, and schizophrenia, for example, might all be disabilities, but they might need to be modeled in different ways. Users/survivors reject strict biomedical interpretations because they view them as reductionistic of their experiences, and these interpretations overlook first-person reports of flourishing. Social constructionist models of psychiatric disability might therefore be more appealing, but those models will be difficult to defend as well. In the disability studies literature, problems with extreme biomedical

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69 My use of the feminine pronoun throughout is not meant to suggest that only women experience psychiatric disability.
and social constructionist models are widely acknowledged. Less extreme models are not well-developed for psychiatric disability, however. Most users/survivors do not proclaim antipsychiatry views, and many of them accept a role for psychiatric interventions for individuals who want them, but they are left without a clear disability model. Their views do not neatly fit within biomedical or social constructionist models. Philosophical work is needed to show what an alternative disability model would look like for psychiatric conditions.

Preemptive Paternalism and Conflicting Claims to Epistemic Authority

Individuals with psychiatric diagnoses often experience preemptive paternalism, even when they believe they can speak authoritatively about their own condition. This paternalism is preemptive because of the stance that others tend to take toward those they think are not reliable reporters of their own experiences, needs, values, and interests. This stance encompasses a host of attitudes and behavioral dispositions. For example, in clinical contexts, this stance could involve presumptive distrust, increased protective inclinations, starting escalation procedures quickly after the patient disagrees with diagnosis or treatment, and immediately reinterpreting what the patient says rather than taking it at face-value. Preemptive paternalism can be reasonably justified in some cases, as when a patient is having a severe psychiatric episode that profoundly distorts reality and diminishes the individual’s agential capacities. However, whenever an individual with psychiatric disability believes that she can testify to her experiences and her values more authoritatively than anyone else, the paternalistic stance will pose epistemic and ethical problems.
Epistemically, there is a question of whose testimony should be believed in cases of conflict. What makes someone an expert regarding psychiatric disability? It is openly debated by users/survivors how to define ‘knowledge’ and ‘expertise’ in ways that do not marginalize or silence; along similar lines, they point to the power involved in being able to authoritatively prioritize some forms of evidence over others. They believe empowerment and ultimately recovery are only possible with the “recognition of their local, regional, experiential knowledge as knowledge and not only as data for the psychopharmaceutical research-industrial complex.”\(^\text{70}\) Peer support in their newly found epistemic community through user/survivor groups can go a long way toward reinforcing each other’s perspectives and expertise, which in turn can support mental diversity.

On the other side, mental health professionals and other “outsiders”\(^\text{71}\) might believe that they have a more accurate view of what the psychiatric condition is. Based on empirical data, published studies, and experience with patients with these conditions, for example, health professionals could come to the conclusion that they have a firmer understanding of what to expect with any given psychiatric condition. When a professional has a long-term relationship with a patient, the professional will also be able to witness any fluctuations and episodes over time, keeping track of triggers and lapses in capacity (if they occur) and any changes in the patient’s preferences. The professional, therefore, might have important understanding about any individual’s particular experiences with her psychiatric condition. When the patient and mental

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\(^\text{70}\) Morrison 23  
\(^\text{71}\) This is not to deny that someone could be a mental health professional and a former or current psychiatric patient. Some users/survivors are self-proclaimed radical mental health professionals, though the majority of users/survivors are not.
health professional disagree on the nature of the psychiatric condition or what should matter for the patient’s recovery, their different epistemic vantage points can pose a significant problem for knowing how to proceed.

These epistemic hurdles are connected to ethical challenges. Preemptive paternalism could seem justified when trying to care or provide for individuals with psychiatric disabilities; this stance could increase the chances of addressing these individuals’ actual needs, regardless of what they say their needs are. Arguably, when faced with individuals with uncertain epistemic standing, preemptive paternalism is the ethically appropriate side on which to err. In contrast, users/survivors suggest that this sort of stance is offensive, stripping former and current patients of their moral status as persons. Especially given widespread misconceptions and stereotypes, individuals with psychiatric diagnoses often do not receive opportunities to prove their ability to participate in decisions as equals. Users/survivors insist that individual patients are in the best epistemic position to say what their interests and needs are, so, ethically, they should be given the chance to advocate for themselves. They want their own values – not the values of people who have ableist or ‘sanist’ tendencies—to guide these decisions. This ethical tension will be pronounced in numerous situations, whether at the level of policy or at the level of treatment decisions.

**Generative Madness and Concerns about Abandonment and Neglect**

Many psychiatric users/survivors embrace a notion of “generative madness,” a term introduced by Bradley Lewis to capture the notion that “psychic difference is something to value,
to be proud of, to channel, and even to enhance.” If a psychiatrically disabled mode of being can be just as valuable as any other mode of being, then that would suggest that medical interventions should not be offered. But especially given the long-term vulnerability and dependency of some individuals with psychiatric disabilities, forgoing medical interventions leads to concerns about health care professionals, institutions, and policies contributing to abandonment or neglect of individuals in need. If someone claims to value her psychiatrically disabled mode of being, to what extent ought that personal value be accommodated by those who are obligated to protect these individuals? Some users/survivors argue that non-interference is morally required, at least in some cases; that is, they argue that their personal values should not be interfered with, and they should be absolutely allowed to pursue their disabled mode of being. For example, Judi Chamberlin argues that “users see ‘involvement’ as nothing less than full and complete decision making power over such fundamental questions as whether to be engaged in mental health treatment, the type(s) of treatment desires, the duration of treatment, where to live, whom to associate with.”

Non-interference is ethically problematic for a number of reasons. Mental health professionals have role-based obligations that include a duty to rescue when they are positioned to use their skills and resources to save a patient from a medically unsafe situation. If a psychiatrically disabled mode of being serves some of a patient’s interests but is detrimental to others, then one question is how to weigh these interests, and another question is what the obligations of the health care professional are in the situation. Non-interference would mean that

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72 Lewis 145
73 Chamberlin, “User/Consumer Involvement” 11, emphasis added
the patient is left unassisted to reason through any potential harms of the disabled mode of being. If the patient’s decisional capacity waxes and wanes, then non-interference would mean allowing the patient to decompensate when she is not in a position to advocate for herself.

Moreover, the very notion of “generative madness” will be incoherent according to standard interpretations of mental illness. Whenever a patient claims to flourish in virtue of a psychiatric condition, health care professionals and others might take this as evidence that the patient is deluded, confused, and in need of medical interventions. From the patient’s standpoint, any medical intervention that threatens her valued mode of being would pose significant harms to her. The relevant harms have to be identified and explored, or else distrust and non-compliance should be expected. The ethical complexities of this situation need philosophical analysis, particularly given how this tension can undermine any therapeutic alliance.

**Methodology and Roadmap**

Philosophers have largely ignored the psychiatric user/survivor movement. Although antipsychiatry received attention in its heyday, the evolutions of the movement and the various claims of these groups have not been unpacked for the most part. This movement deserves philosophical and bioethical attention, given that these activists believe they are identifying significant harms to anyone suspected or diagnosed with mental illness, and these harms crop up in disorder classification, hospital procedures, therapeutic goal-setting, and elsewhere. Moreover, the nuances of their claims and demands (e.g., to what extent equal participation in clinical
decisions is ethically called for) need exploration. Below I describe my methodology for the remaining dissertation, and I summarize my arguments in each chapter.

**Tools of Bioethics and Disability Studies**

The philosophical tools implemented throughout this dissertation bring together the insights of bioethics and disability studies. Sara Goering suggests that bioethicists are inclined to make two erroneous accusations of disability perspectives: an accusation of denial and accusation of lowered expectations. On the former, “the bioethicist implies that the satisfied person with an impairment is in denial about what she really prefers.”\(^74\) Bioethicists who make this accusation (outright or by implication) reveal that they privilege normality and have an overly narrow view of what constitutes flourishing. The presumption is that any individual with a disability would admit that she would accept a magic cure were it available. Underlying this presumption is “an implicit (and troubling) view that ranking individuals according to quality of life is not only possible but inevitable.”\(^75\) Disability scholars and bioethicists can quickly find themselves in conflict when it comes to quality of life judgments. In the case of the second accusation, “the bioethicist may recognize an individual’s sincerity of belief about quality of life with an impairment, but argue that any preference for this way of living are likely the result of lowered expectations given the limited opportunities inherent in living with an impairment.”\(^76\) This way of thinking exposes a highly paternalistic stance, as it presumes that anyone who

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74 Goering, “‘You Say You’re Happy, but…’” 126
75 Ibid.
76 Ibid.
claims to flourish in virtue of an impairment simply does not know any better. With these two accusations, we can see how subjective reports and narratives are systematically dismissed. Individuals with psychiatric disabilities face similar difficulties in having their perspectives respected. A bioethical analysis of these issues should take care to avoid these accusations and erroneous presumptions.

Anita Silvers outlines some central goals for achieving a mutually respectful dialogue between bioethicists and disability activists—and I would extend these goals to user/survivor activists as well. These goals involve neutrality in 1) valuing disability, 2) modeling disability, and 3) adopting a cooperative framework.

First, the analysis needs to be rid of the assumption that “reducing the incidence of disability is unquestionably good”, and all people with disabilities desire a cure for their condition. To accept this, bioethicists would need to understand that “nondisabled people commonly suffering from a very limited imagination regarding our abundant possibilities for achieving satisfaction in life”. The implications of this epistemic barrier would need fuller acknowledgement than is found in most bioethics scholarship. But while the value of normalcy should not be overinflated or universalized, disability activists should not “presumptively declare that medical interventions aimed at eliminating disabilities present bias against disabled people.” Some impairments are severe enough that social accommodations will be inadequate

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77 Silvers, “On the Possibility” 475
78 Ibid.
79 Ibid. 476
for the life to be one of flourishing. How one person’s life with a specific disability ought to be evaluated will depend on a host of particularities.

Second, productive dialogue about disability should not presume a medical or social constructionist modeling of all disability. A neutral framework would not “deny that disabilities can be health issues, but instead […] acknowledge they are neither necessarily nor mainly so.”\(^80\) This neutrality encourages openness to the narratives of individuals who have their own experiences with disability. Silvers comments that “impairments may be an absence, deletion, omission, reduction, or diminution […] impairments are anomalous in that they differ from what is typical, but anomalies are not necessarily harmful, disadvantageous, or otherwise bad.”\(^81\) It is common to think that any kind of limitation in ways of living, agency, and choice is intrinsically undesirable. However, limitations are inevitable with any mode of being; some of these will hinder a person’s ability to attain basic goods or to exercise her autonomous capacities, but others will not threaten a meaningful life. There needs to be care to avoid the “logical mistake about the disability classification by taking a part to be the whole.”\(^82\) In other words, even though some impairments are inherently painful and undesirable, it would be an error to assume that this characterization is true of all impairments and vice versa. Shedding preloaded presumptions about living with impairment means that scholars and activists can have an “open process of weighing value, for whether a particular physical or cognitive difference is unfavorable should be an open empirical question, not one closed by social convention.”\(^83\)

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\(^80\) Ibid. 477  
\(^81\) Ibid. 479  
\(^82\) Ibid. 478  
\(^83\) Ibid. 479
Lastly, a cooperative social framework “will identify justice with the most maximally rewarding inclusive scheme, not with divisive schemes that entitle some privileged individuals to maximal benefit.”84 In order to achieve just arrangements and practices, problematic norms, such as those surrounding species-typicality, need to be identified and questioned. The great diversity of human embodiment and cognition needs to be respected and celebrated when those modes of being are valuable to those who experience them. Inclusivity should be the prevailing standard, Silvers argues, not the maximization of privilege. Bioethicists would need to take a critical lens to ableist attitudes that pervade medical practice; disability activists would need to advocate for equity and not special treatment status that insists on its own privilege. Silvers argues that “privilege is destructive regardless of whether it is claimed by the species-typical majority or a special needy minority.”85

The work I present here goes some way toward answering Silvers’ call for a reconciliation between bioethics and disability activism; I go further by bringing these insights to a philosophical analysis of user/survivor activism. Duties of recognition, elaborated in the third chapter, will highlight the value of inclusivity in just social arrangements. Keeping in mind how psychiatric disability and physical disability are distinctive, I will point out some of the main obstacles to achieving inclusivity and recognition for user/survivors (and others who identify with their aims even if they are not politically active). Neutral valuing and modeling of psychiatric disability will be crucial for making conceptual room for key claims coming from users/survivors.

84 Ibid. 482
85 Ibid.
CHAPTER TWO: CONCEPTUALIZING PSYCHIATRIC DISABILITY

There are numerous terms, often used interchangeably, for what will be the focus of this chapter and dissertation: ‘mental illness,’ ‘mental disorder’, ‘psychological malady’, ‘mental disease’, among others. I will use the term ‘psychiatric disability’ in the stead of all these others. This choice of terminology is rooted in my aims both to take advantage of disability frameworks for conceptualizing these conditions and to take steps towards reducing negative connotations and stigmas generally associated with mental illness. Undoubtedly there are philosophers, bioethicists, and clinicians who view disability and impairment as inherently negative (read: undesirable, painful, lesser-than) conditions that individuals suffer from; however, scholars and activists within the field of disability studies have long insisted that impairment in itself does not necessarily preclude flourishing, and instead it is factors external to the individual that are often disabling. We can see these arguments developed in their analyses of how to model disability.

I argue that interactionist disability modeling accommodates some of users/survivors’ central claims, but it also provides a dynamic and complex picture of psychiatric disability that is more accurate and precise than its competitors. Interactionist models are importantly neutral in

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86 My evasion of the terms ‘mental illness’ and ‘mental disorder’ should not be construed as a rejection of the reality of these conditions. Also, psychiatric disabilities are distinct from cognitive disabilities. ‘Cognitive disability’ has numerous definitions, but generally they involve significant intellectual deficits (measured in terms of IQ—see Cantor 1-2) and can also result from developmental problems (genetically, in utero, in infancy, from diseases) (see Ohio Coalition for the Education of Children with Disabilities; Wasserman et al. 5-6). Norman Cantor’s book, Making Medical Decisions for the Profoundly Mentally Disabled, is about profoundly cognitively disabled individuals—not about mental illness. I will not use the term ‘mental disability’ to avoid confusion. ‘Psychological disability’ and ‘psychiatric disability’ can be used interchangeably, though I will use the latter, since the latter is used more frequently in the (limited) literature on this topic (see Asch, “The Experience of Disability”; United States Equal Employment Opportunity Commission; Sykes et al.; Jones & Brown). My use of the term ‘disability’ will be more expansive than some legal interpretations of the term (similarly, the disability scholars who analyze psychiatric conditions are not only talking about the narrower set of impairments that are covered by the ADA or any other piece of legislation).
how they evaluate the impact of disability for someone’s flourishing potential, which sets the stage for the remaining chapters of this dissertation.

In this chapter, I begin by laying out fundamental aspects of disability modeling. I explain the distinction between impairment and disability, and I describe the functions of disability modeling. In my discussion of how these models function, I build off Anita Silvers’ work and demonstrate the evaluative function of these models as well. I defend disability modeling for psychiatric conditions, even though this interpretative framework is generally only used for physical conditions. From here, I explain biomedical and social models, which are the most prominent in this area of scholarship. Although biopsychosocial models of physical and psychiatric disability have been proposed through the years, disability rights activists and users/survivors have not widely adopted this hybrid approach. Historically, users/survivors championed social constructionist modeling, but I explain why this view is problematic and unhelpful for their activism. I illustrate how interactionist models function and how they avoid the failures of other models. I close by analyzing the implications of interactionist modeling for the user/survivor movement.

IMPAIRMENT, DISABILITY, AND THE FUNCTIONS OF MODELS

A model “is a complex, integrated system of meaning used to view, interpret, and understand a part of reality.” Rather than offering necessary and sufficient conditions for a

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87 An early version of these arguments received comments from participants at the 2014 meeting of the Association for the Advancement of Philosophy and Psychiatry. The modified paper has been published in Journal of Evaluation in Clinical Practice, and I am additionally grateful to the reviewers and editors for their feedback.

88 Veatch, “The Medical Model” 108
definition of a concept, modeling\textsuperscript{89} provides an interpretative framework. Different models will vary in what they highlight or bring into focus, as well as which comparisons and contrasts are possible or intelligible. Models do not provide a comprehensive, all-encompassing account. Rather, some interpretations will not be prioritized and could even be hedged out of the picture. This feature is what makes a model a model; it is not infinitely flexible to accommodate all potentially relevant perspectives and values equally. Embracing a new model means accepting a different orientation and fundamentally changing one’s value-based commitments and way of interpreting the phenomenon under consideration. Different models will be serviceable for different purposes. When choosing a model, we need to consider what our purposes are or should be. These points will become clearer as we go through the different foci of the competing disability models.

In introducing disability models, I first explain the distinction between impairment and disability. While some models view them as coextensive with the same cause(s), other models provide vastly different accounts of what it means to be impaired and what is means to be disabled. I then outline the functions of disability models, which will guide my analysis of the models in subsequent sections. Models reveal what disability is (and who is considered to be disabled), why disability occurs, and how disability affects flourishing potential.

\textsuperscript{89} Silvers suggests that the biomedical and social models of disability (explained below) do not qualify as true models. She defines ‘model’ as “a standard, example, image, simplified representation, style, design or pattern, often executed in miniature so that its components are all easy to discern” (Silvers, “An Essay on Modeling” 22). She states that the social and biomedical do not offer representations. However, she goes on to identify functions of models, since the social and biomedical approaches fulfill many of those functions.
Distinction between Impairment and Disability

Disability models distinguish between disability and impairment. Historically, scholars within disability studies have treated impairment as a biological given; impairments have been generally viewed as biological limitations or dysfunctions that tend to be within the purview of medical diagnosis and medical amelioration. In the 1976 *Fundamental Principles of Disability*, the Union of the Physically Impaired Against Segregation (UPIAS) defined ‘impairment’ as “lacking part of all of a limb, or having a defective limb, organ or mechanism of the body”. Similarly, The World Health Organization’s 1980 *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) says impairment consists in “any loss or abnormality of psychological, physiological or anatomical structure or function.” Designating a condition as an impairment relies on judgments of what is normal, healthy, or typical for the species or for that individual’s social group or demographic.

Impairments can be genetic, sudden or degenerative, early-onset or late-onset, or painful. Illness (at least some illnesses) can be considered a form of impairment. Individuals with chronic or severe illness can have similar experiences of disability, and they often face barriers to equal participation and access as a result of stigma and ableism. As Wendell nicely puts it: “so

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90 Modeling of disability had its beginnings in the work of Michael Oliver, who has provided fruitful sociological analyses since the 1980s. The precise delineations among orientation, interpretation, model, and theory are not central to my analysis.
91 Union of the Physically Impaired Against Segregation 14
92 World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps* 27
93 See discussion and analysis of this point in Boorse; World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps*; Wendell; Gert, Culver, & Clouser; Silvers, “An Essay on Modeling.”
94 The connection between illness and impairment has been contested, though. For example, Ron Amundson argues that ill people suffer from “global incapacitation” and require significant medical intervention, but it is damaging and inaccurate to view individuals with impairments in the same way (21-22). Amundson’s concerns about associating illness with disability overlook the ways in which illnesses and impairments can vary; not all illnesses will lead to global incapacitation, and some impairments will.
many people with disabilities also have health problems, and so many people with illnesses are
disabled by their illness, that it seems to make sense to make common cause on these issues by
recognizing them as aspects of access to opportunities for people with disabilities.”

Within disability studies, most research and theorizing have been centered on the
meaning of disability, since impairment is taken to be a) a biological given and b) an imprudent
focus of scholarly activism, since it could overemphasize physical limitations and reinforce
overly narrow medical conceptual schemes. We can see considerable divergence in conceptions
of disability. The ICIDH describes disability as “any restriction or lack (resulting from an
impairment) of ability to perform an activity in the manner or within the range considered
normal for a human being.” So whereas impairments are viewed as biological losses or
limitations, disabilities are viewed as limitations that specifically have negative repercussions for
everyday life or meaningful activity. The ICIDH’s framing of disability has been roundly
criticized for its bio-physiological assumptions about normality, for privileging species
typicality, and for glossing over how limitations can be felt differently by people who are
differently situated (even if impaired the same). Moreover, the ICIDH has been accused of being
too inattentive to the social and cultural factors that can largely determine which limitations are
experienced and the import of those limitations. The ICIDH does suggest a third concept to try
to take account of this worry: “a handicap is a disadvantage for a given individual, resulting
from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal

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95 Wendell 21
96 See, e.g., Mulvany 588
98 See, e.g., Wendell 14; Williams, Gareth 128; Barnes & Mercer 14; Oliver & Barnes 17-20.
(depending on age, sex, and social and cultural factors) for that individual”. The addition of the handicap concept does not alleviate the concerns of most disability activists and scholars, however, since the ICIDH insists that disability and handicap are “resulting from an impairment”—rooted in biological dysfunction rather than any sociocultural dysfunction, dysfunction of the individual rather than dysfunction of the society.

Anita Silvers explains:

In contemporary Western culture, to be disabled is to be disadvantaged regardless of how much success one achieves individually. [...] ‘disability’ now is associated with physical or mental differences that compromise people’s liberty to achieve typical levels of success in one or more areas of social participation, whether the relevant activities are learning, communicating, mobilizing, communication, being employed or some other important productive activity. The key phenomenon that informs this idea is the experience of disabled people’s being more limited than other people in one or more seemingly important respects.

According to the dominant cultural narrative, everything else being equal, no rational person would want disability themselves or for their loved ones. Disabilities are viewed as problematic limitations that hinder worthwhile life pursuits or disrupt end-setting. On this pervasive cultural interpretation, a disability is something wrong with the individual. Disability models differ in the extent to which they attribute suffering and life impediments to fixed conditions of the individual or to contingent social circumstances. Rejecting the ‘handicap’ concept for being useless and

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99 World Health Organization, *International Classification of Impairments, Disabilities, and Handicaps* 29, italics added
100 Silvers, “An Essay on Modeling” 23
obfuscating, disability activists and scholars focus their attention on the relationship between impairment and disability.\(^{102}\)

\[\text{Functions of Disability Models}\]

Anita Silvers identifies two main functions of disability models. For one, they shed light on who counts as having a disability, which means giving insight into what disability is. Two, they also are supposed to explain why someone becomes disabled, which involves identifying relevant contributing factors and drawing a line (directly or indirectly causal) from those factors to the experience of disability. I contend that there is a third function, an evaluative one: Disability models provide a critical lens for considering the impact of disability for someone’s quality of life. I will explore all three of these functions in more detail, which will provide the backdrop for my subsequent analysis of competing disability models.

First, models are used to “characterize disability identity and sometimes also to determine who is eligible to assume this identity.”\(^{103}\) Depending on the model, different properties will be marked out as most relevant for determining who is disabled and what it means to be disabled, and paradigms or exemplars can provide reference points for helping to discern when disability occurs. Is disability identity primarily one of biological aberration or defect? Is it a suffering, pitiable state? Is it a minority status? Is it a mark of victimhood or vulnerability? Certain

\(^{101}\) Wendell 23; Boorse, “Disability and Medical Theory” 58-59  
\(^{102}\) The distinction between impairment and disability and questions about their relationship were born in theorizing about social models of disability specifically. However, as biomedical models and middle-ground models have proliferated, we can see further elaborations on the relationship between and meaning of impairment and disability.  
\(^{103}\) Silvers, “An Essay on Modeling” 22
responses to these questions will threaten to essentialize difference and totalize\textsuperscript{104} the identity of individuals with disabilities; in other words, disability could be seen to overwhelm all other aspects of the person’s identity, reducing her sense of self to elements of disability.\textsuperscript{105} Studies have found that individuals without disabilities “frequently cannot focus on any of the other personal characteristics—those they would customarily use in evaluating people and in creating interpersonal relationships—in encounters with disabled persons; they see only the disability,” even when the disability is not visible.\textsuperscript{106}

Further, some responses to the above questions can end up denying individuals’ experiences and self-knowledge claims. If a model frames disability identity in a way that does not fit with how someone with a disability views herself, then she is faced with either rejecting her disability status or refuting the model, and either option could end up alienating her from her own experiences. Wendell reminds us that people can be misidentified as having a disability, either by themselves or by others. When correctly identified, “your experience of your own body is (at least to some extent) recognized by your society and the people who surround you; denial of their experience is a major source of loneliness, alienation, and despair in people with unrecognized disabilities”.\textsuperscript{107} The “who/what” dimension of modeling marks the boundary between those with disabilities and those without, so there are also concerns about where the

\textsuperscript{104} See discussion about the totalizing of identity in Wendell and Shakespeare.
\textsuperscript{105} This kind of worry is what has prompted many disability theorists and activists to speak now of “persons with disabilities” as opposed to “disabled persons;” the former is thought to emphasize that a disability is something someone has, not what someone is. Similarly, there is a rejection of phrases like “the disabled,” “the epileptics,” and “the schizophrenics.” See, e.g., Shakespeare, “Disability, Identity and Difference.”
\textsuperscript{106} Asch, “The Experience of Disability” 531
\textsuperscript{107} Wendell 25
boundary lies and how bold the line is. Who qualifies as disabled and when disability occurs could be somewhat flexible, fluid, and changing.

Second, models help explain “why [individuals with disabilities] have the limitations associated with disability.”\textsuperscript{108} Models will differ in what they locate as the central cause(s) or main contributing factors of disability, as well as the appropriate methods for intervening in these processes or factors. A model may present a simplified explanatory story, excluding many potential factors that seem irrelevant or imprudent to highlight. When a model completely diminishes certain factors, it will fall on one of the extreme sides of the spectrum of modeling. Rather than \textit{exclude} factors, most models \textit{stress} some factors over others as primary. When it comes to competing models, “the controversy reflects conflicting intuitions about how much each type of factor contributes” to the occurrence and experience of disability.\textsuperscript{109} Certain factors are highlighted as deserving the most attention, since they are the most disabling, the most pertinent, and the most promising starting place for successful interventions meant to assist or accommodate this population. Silvers points out that the model chosen by activists will be the one that proves most serviceable politically, even though no reasonable model would deny that there is a variety of relevant factors to how someone becomes disabled.\textsuperscript{110}

When disability is seen as a necessary consequence of impairment, the explanatory stories for both will be tightly linked. Alternatively, models can provide vastly different explanations for why impairment occurs and why disability occurs, suggesting that impaired

\textsuperscript{108} Silvers, “An Essay on Modeling” 22
\textsuperscript{109} Wasserman 226
\textsuperscript{110} Silvers, “An Essay on Modeling” 30
persons are not inherently disabled by their condition. Does disability occur simultaneously with
the onset of impairment, or is it instead the result of complex sociopolitical factors? Depending
on which causes or contributing factors are identified, a model indicates what needs to be
alleviated or remedied, thus providing guidance for treatment planning, priority setting in health
care, and other policies. Why one model is chosen over its competitors will be based on the
particular aims of the one using the model, since the “who/what” question might matter more or
less than the “why” question.111

I contend there is a third function of disability modeling: They have an evaluative role in
suggesting how the disability affects the individual’s flourishing potential,112 which in turn has
implications for what is in the patient’s interests. This aspect of modeling is sometimes explicit,
sometimes implicit. As a byproduct of the first two purposes (identifying who qualifies and why
the condition exists), the models will inevitably assign a sort of responsibility to the patient, the
patient’s biological mechanisms, or the society at large. This responsibility might not be moral
responsibility, though moral judgments can arise in certain contexts if, for example, a patient
does not seek professional help for a diagnosed condition and is seen to be burdening others as a
result. Assigning this responsibility matters because disability is relevant for something of
fundamental value—namely, the individual’s flourishing potential. Not every loss, limitation, or
atypical feature will be marked as impairments, and not all will be associated with disabilities.

111 For example, someone working on a court case under the Americans with Disabilities Act would presumably be
more interested in the former; a biochemical researcher might be more interested in the latter.
112 I say “flourishing potential” because the issue is not whether someone with a disability is currently flourishing
but whether she could flourish in virtue of or despite her disability. I use the term ‘flourishing’ broadly throughout
this dissertation. I do not mean it to be interchangeable with the concept of well-being, since, as I show in chapter
four, I believe there are other valuable aspects of life that are not reducible to well-being concerns (depending on
how ‘well-being’ is conceptualized). A broader notion of flourishing could cover these other aspects of valuable
living.
For example, male pattern baldness, unusually small feet, and excess body hair are not generally viewed as impairments with associated disabilities. As mentioned previously, disabilities are thought to indicate *problematic* limitations; what makes them problematic would be how those limitations affect agency and flourishing potential.

Regardless of whether the model will be used for public health, clinical, legal, advocacy, or research purposes, one of the main reasons to bring a model to bear on the relevant questions is for the sake of pinpointing what needs to be fixed or remedied. How disability relates to flourishing will determine what is judged to be in need of fixing. Depending on the model, we would expect different answers to the following: How can individuals with disabilities overcome, manage, or flourish in respect to their condition? What should society or particular institutions aim to provide in the name of just accommodation and respect? Are persons with disabilities expected to struggle or suffer as long as they have impairments, or is some form of recovery possible even when impairments persist?

The evaluative function of modeling has overlap with the other functions. For example, depending on the evaluation of these conditions, impairment and/or disability could be interpreted as undesirable states of deficiency or as valuable modes of human diversity. If a lower quality of life is inherent to impairment, then recovery from and just accommodations of disability will need to make it possible for someone to overcome the limitations and pain posed by the impairment. If an impairment is valued by many individuals who have that impairment, and if problematic limitations that these individuals experience instead arise largely from environmental factors, then recovery and just accommodations will need to aim at making it
possible for someone to flourish with her impairment—which means changing external conditions (at least primarily).

In all of the models, values are apparent. By highlighting some features of the phenomenon of disability over other features, models give more weight to certain perspectives, interests, and forms of expertise over others. In disqualifying certain persons from claiming a disability identity, for instance, a model might give priority to biomedical criteria or subjective reports of those living with the conditions. Disability models are deeply normative, and which model is chosen reveals which values are being weighed, neglected, and favored. As put by Silvers, choosing a model “is to some extent a practical one”, but “it also is a matter of who is valued”—those who “approximate the typical person” or those who do not fit able-bodied norms. This latter point about whose perspectives and experiences are valued will become clearer in the comparison of models in the next section. Of course, those who defend models that are contrary to disability activists’ preferred models would insist that they are not disvaluing people who are atypical or not able-bodied. Generally, we can have a more nuanced and charitable take on these different models if we view them as ranking values differently; just because certain values or concerns are ranked higher than others, it does not necessarily mean that persons or perspectives are being wholly disvalued or ignored.

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113 Tim Thornton suggests that models can be non-evaluative or value-free (242). I will demonstrate that models that seemingly eschew evaluative questions, like biomedical models, actually are privileging some values and perspectives over others.

114 Silvers, “An Essay on Modeling” 30
DISABILITY MODELING FOR PSYCHIATRIC CONDITIONS?

Physical\textsuperscript{115} conditions and psychiatric conditions differ in important respects. As will be discussed further in other chapters, psychiatric conditions can diminish someone’s agency, epistemic standing, and capacity to value. Moreover, psychiatric episodes can affect everyday living in vastly different ways for the same individual over time. The episodic nature of many psychiatric conditions can make identity and quality of life fluctuate, and these fluctuations could be relatively small or significant. Physical disabilities generally do not have these features. These differences do not suggest that psychiatric conditions cannot be modeled in a similar manner as physical conditions, however.

A successful model of psychiatric disability will need to be complex and dynamic, and it might need to account for episodic fluctuations. Disability models do not need to be simple and rigid in how they function, so there is no reason why disability models could not capture psychiatric conditions. \textit{What} is disabling at any given time for an individual with a psychiatric condition does not demand a single, fixed answer. The disabling features might vary according to a host of factors, some of which could be more prominent at some times than others. \textit{Why} a psychiatric disability occurs can refer to a multitude of variables, includes those that trigger episodes. The \textit{evaluation} of how the disability affects flourishing potential can be fine-grained and particular, considering (e.g.) what resources are possible during episodes, whether a

\textsuperscript{115} Cognitive and intellectual disabilities are often left out of these discussions of disability models. Although it is unfortunate to exclude them again, this is outside the scope of my dissertation.
psychiatric advance directive exists to help manage the condition, and the level of fragmentation\textsuperscript{116} that is associated with the condition.

The conceptual distinction between impairment and disability is helpful for interpreting psychiatric conditions. We can separate, to a certain degree, our research questions and types of concerns based on whether we are inquiring into someone’s psychiatric impairment or psychiatric disability. For example, new scientific knowledge and medical treatment possibilities regarding the progression of psychiatric impairments do not eliminate concerns about how certain limitations and difficulties can arise due to factors that are not directly caused by the impairment. What is disabiling for individuals with psychiatric impairments remains a question worth investigating, since the disability could be importantly separate from the impairment. The discovery of statistically abnormal neural pathways or chemical imbalances that are hypothesized to underlie certain psychiatric conditions might be enough to diagnose someone with an impairment; the question of whether that individual will have a diminished quality of life is distinct, and it could largely depend on factors external to the individual. By conceptualizing these conditions as types of psychiatric disability and by using disability modeling, therefore, we can separate these questions, at least initially. This tactic will help us steer clear of loading our conception with pre-theoretic assumptions about the experience and meaning of mental illness. Disability modeling offers a more nuanced and neutral framework for these psychiatric conditions.

\textsuperscript{116} I discuss concerns about fragmentation more in the next chapter.
In a 2009 *Hastings Center Report*, Alison Jost dismisses similarities between physical conditions and psychiatric conditions, and she suggests that it would be irresponsible to frame mental illness as anything besides a harmful and dangerous disorder. She argues that “[n]o matter how destigmatized our society becomes, mental illnesses will always cause suffering. They are not simply different ways of processing information or emotion; they are disorders in the capacities for processing information or emotion.”\(^{117}\) It is difficult to read Jost’s argument as anything besides question-begging. As described previously, activists in the psychiatric user/survivor movement believe, *contra* Jost, that their conditions do not necessarily cause suffering. Their modes of being can be valued similar to how deafness is valued by those in the Deaf Gain movement: “Just as some deaf activists prefer to embrace their inability to hear rather than ‘cure’ it with cochlear implants, members of Icarus [and similar groups] reject the notion that the things that are called mental illness are simply something to be rid of.”\(^{118}\) Activists in all of these groups share a commitment to rethinking or overhauling the received view on how to interpret their conditions or impairments.

Disability models help reveal points of tension regarding what counts as psychiatric disability (and who qualifies), why psychiatric disability occurs, and how it could affect flourishing potential. Just as disability activists and scholars challenged notions of what is *inevitable* and *intrinsic* to physical impairments, users/survivors challenge common notions of mental “disorders.” Before dismissing their claims out of hand based on standard notions of what

\(^{117}\) Jost c3. In her critique, Jost focuses on mental illnesses that lead to death from suicide or starvation (as in anorexia). It is unclear whether she believes that all mental illnesses threaten life or if she has reasons for distrusting reports from users/survivors about their quality of life with their conditions.

\(^{118}\) Quart n.pg.
counts as abnormal and deficient, it is worth analyzing psychiatric conditions according to disability models.

**COMPETING DISABILITY MODELS**

The existing literature on disability models mostly focuses on biomedical and social models. I give an overview of these models, contrasting the importantly different ways in which they function. These differences have implications for how disability should be treated and accommodated. As they are commonly portrayed, biomedical and social models have deep tensions that are not easily reconcilable. If health care professionals and disability activists approach the notion of disability through the lens of opposing models, then each group will struggle to have their expertise and values given the weight they believe they deserve. This background on biomedical and social models therefore sets the stage for my proposed hybrid approach.

**Biomedical Models**

Biomedical models describe disability and correlated deficiencies in quality of life as a direct and inevitable result of the impairment (e.g., the paralysis, limb loss, deafness). The causal story begins with and continually emphasizes the role of biological, physical factors. Impairment and disability are viewed as coextensive. Biomedical models are also sometimes referred to as individual models, since the “disability is regarded as a problem at the individual (body-mind)
level”. This view of disability “is routinely reaffirmed by the activities of policy makers, professionals and mainstream scholars and researchers who in one way or another explain disability in terms of medical diagnoses of individual pathology.” The ICIDH would be considered a type of biomedical model, since it attributes the occurrence of disability to individual impairment.

According to biomedical models, the disadvantages of disabilities are “exacerbated, but not created, by neglect and exclusion.” Biomedical models can consistently acknowledge the importance of discrimination, stigma, and other sociocultural and political factors that impact the lives of people with disabilities. The suffering and limitations that someone experiences with a disability could be partly explained by these environmental factors. However, according to biomedical models, impairment always threatens quality of life and the ability to function well in society, regardless of how accommodating their environment is.

Biomedical models frame disability identity as one of personal tragedy, as an unfavorable mode of being rooted in biological deficits. To have a disability is to suffer from a biological limitation that significantly falls outside of species-typicality, statistical normalcy, or what is generally desired for basic actions and functioning. The problem of disability is totemized within the individual rather than in the intersection between the individual and her context. To determine normal/non-disabled and abnormal/disabled functioning or physicality is controversial. For some discussion, see Wasserman.

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119 Barnes & Mercer 2
120 Oliver & Barnes 11
121 Mike Bury comments: “It has therefore been ironic, over the years, to see the ICIDH characterised by some as a ‘medical model’, when the intention and the effect of the ICIDH was quite the opposite. The desire to challenge discrimination and disadvantage were at the heart of the ICIDH” (1075).
122 Wasserman 221, emphasis added
123 What should be the baseline for determining normal/non-disabled and abnormal/disabled functioning or physicality is controversial. For some discussion, see Wasserman.
124 I am grateful to Alisa Carse for suggesting this concept to me.
protect the interests of individuals with disabilities according to this type of model, the root problem of impairment needs to be addressed by health care professionals. Accommodations should strive to make medical interventions feasible and accessible, and for people who cannot receive medical assistance, accommodations should be provided to help them live as well as possible despite the confines and the pain of their condition.

Although proponents of biomedical modeling often claim that it is value-free and objective, “they also tend to regard normal functions as presumptively desirable and many, though not all, impairments as disadvantageous in causing various limitations and in denying or restricting valuable experiences or opportunities.”¹²⁵ A defining feature of biomedical models is that impairments are seen as disabling defects, as limitations that are harmful by closing off valuable opportunities or diminishing functioning, which has implications for the evaluative function of this type of model. According to Talcott Parsons, patients diagnosed with a biological ailment (within a biomedical model) occupy the sick role. The sick role exempts the individual from normal social responsibilities (that she would have if it were not for the sickness) and responsibility for her sickness (since it is due to mechanisms that cannot be merely “willed” toward health). As a result, biomedical models have the potential to alleviate stigma associated with disability. However, the sick role does make the patient responsible to “‘seek technically competent help’” and to try to return to a healthy state.¹²⁶ On this type of model, since impairments threaten flourishing, the optimal scenario for individuals with disabilities will be flourishing despite their condition. To recover from her condition, the “disabled person is

¹²⁵ Wasserman 221
¹²⁶ Parsons, qtd. in Veatch, “The Medical Model” 111
expected to make the best of their diminished circumstances and focus on individual adjustment and coping strategies with appropriate professional direction”.127 As far as what counts as high quality of life, standards are set by referencing conditions that are not impaired.

Social Models

In contrast, social models separate impairments and disabilities; they are not coextensive, meaning someone can be impaired without being disabled. On this type of model, ‘impairment’ designates a biological condition, whereas ‘disability’ signifies a sociopolitical condition.128 The extent to which someone is disabled by her social circumstances will be contextual:

the disability in a given situation is often created by the inability or unwillingness of others to adapt themselves or the environment to the physical or psychological reality of the person designated as ‘disabled’; and people with disabilities often regard the accommodations they make to their physical conditions as ordinary living arrangements and their lives as ordinary lives, despite their medicalization by professionals and most people’s insistence that they are unusually helpless or dependent.129

In the above quote, Susan Wendell emphasizes that ableist norms are disabling, not just the medicalized condition of the individual. When someone experiences disability, there is not necessarily anything wrong with the individual, but there will always be something wrong with the environment.

127 Oliver & Barnes 19
128 Barnes & Mercer 11; Asch, “Disability, Bioethics, and Human Rights”; Shakespeare; Mulvany; Burchardt; Oliver; Smith, “Social Justice and Disability”; Goering, “Revisiting the Relevance of the Social Model of Disability”; Silvers, “An Essay on Modeling”; Oliver & Barnes
129 Wendell 30
The Union of the Physically Impaired Against Segregation (UPIAS) criticizes proponents of other models for misplacing the why of disability: “The fact that they had delusions that they were looking at the cause, when they were typically concentrating on its effects, or confusing disability with physical impairment, underlines the imperative need for disabled people to become their own experts.” The suggestion of UPIAS, along with many other disability activists and scholars, is that individuals who have never experienced disability have an epistemic barrier to understanding the nature and cause of disability. People with disabilities have an epistemic privilege into their condition, which includes insights into which limitations are significant and from whence disadvantage arises. Discrimination, stereotypes, and stigmas are therefore central to the causal picture.

For biomedical models, some form of negative self-identity—that is, an identity marked by disadvantage and misfortune that one needs to grieve and come to terms with—will be an inevitable consequence of impairment. Social models instead claim that a positive self-identity—an identity that opens doors for novel modes of being, new communities, and empowerment—can be available for impaired persons. Even if proponents of biomedical models insist that they can recognize the empowerment of the disability community, they would nonetheless have to add a “but” in their assessment: They are capable of being empowered as a community, but each individual will necessarily struggle against the pain and limitations posed by impairment.

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130 Union of the Physically Impaired Against Segregation
131 Asch, “Disability, Bioethics, and Human Rights”
132 Shakespeare, “Disability, Identity and Difference”
Social models describe disability identity as one that is ripe for political recognition, as one that ought to challenge ableist presumptions about the meaning of agency and a worthwhile life.

In order to protect the interests of individuals with disabilities on this model, environmental factors have to be targeted. Accommodating disability would mean overhauling the ableist structures of society (e.g., providing sign language interpreters in hospitals and maintaining elevators in public buildings). Social models often rely on an envisioned just society where impaired individuals have all the accommodations that they need, and ableism is completely defeated in every sphere of daily living. In such a society, it is argued, disability would cease to exist; there would merely be a diversity of individuals with dimensions of difference that span across impairments. On the more extreme versions of social modeling, impaired individuals in this just society would not suffer or have a diminished potential for flourishing at all (at least not in relation to their impairment).

Biomedical models and social models fundamentally differ in how they function evaluatively. Social models challenge dominant cultural understandings about what constitutes an unbearable limitation or loss. David Wasserman acknowledges the impairments can impose limitations, but he argues: “The claim that certain impairments preclude valuable experiences does not mean that they thereby make life any less rich or valuable overall; it may rather support the conclusion that there is an indefinite variety of ways in which human lives can flourish.” According to many disability rights activists, impairments can be associated with gifts,

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133 Wendell 32-33
134 Shakespeare, “The Social Model of Disability” 271
135 Wasserman 2001, 222
community, and enriched experiences; thus, it is not the case that all rational people, other things being equal, would take a “magic pill” to rid themselves of their impairment.\textsuperscript{136} Social model proponents emphasize that many perceived features of disability that are deemed to be undesirable—such as losses to independence, self-sufficiency, and control over one’s life—are either a) common facets of human existence, and/or b) do not necessarily pose problematic limitations to individuals with disabilities as is commonly believed.\textsuperscript{137}

In this vein, many disability activists and scholars contend that biomedical models err by misconstruing and over-emphasizing the value of independence and control. As put by Adrienne Asch: “self-direction, self-determination, and participation in decision making about one’s life are more genuine and authentic measures of independence or, better, interdependence. It is no more demeaning to obtain help in dressing or washing from a personal assistant than it is to get services from an auto mechanism, a plumber, or a computer technician.”\textsuperscript{138} Carolyn Ells argues that any lack of control that is associated with impairment if often due to lack of accommodation and inaccessibility. To promote agential opportunities and support flourishing potential, barriers needs to be reduced, and opportunities need to be created, which could require far more perceptiveness and creative problem-solving with environmental factors than is commonplace now.

According to social models, the responsibility does not lie on the individual to get well—the responsibility lies with those who contribute to current oppressive or unjust circumstances.

\textsuperscript{136} Cf., e.g., Goering, “You Say You’re Happy, but...” 131
\textsuperscript{137} See, e.g., Newell 278; Kuczewski, 42; Asch, “Disability, Bioethics, and Human Rights” 300
\textsuperscript{138} Asch, “Disability, Bioethics, and Human Rights” 313

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Moreover, since it is the society that is disabling (and not anything inherent to the condition or originated within the individual), impairments in themselves do not preclude the possibility of flourishing. This evaluative dimension of social models is highly attractive to individuals who value their impairment and care about the mode of being that they otherwise would not have. Based on this type of model, quality of life standards should be largely influenced by the first-person reports of individuals with disabilities, not by outsider judgments of what is normal and abnormal.

**INTERACTIONIST MODELING FOR PSYCHIATRIC DISABILITIES: A PROMISING HYBRID**

We should find a serviceable hybrid (biopsychosocial) model because of the limitations of biomedical models and social models. Biomedical and social models present simplified causal explanations of disability by narrowing in on either biological factors or social factors, but we should expect monocausal accounts to be impoverished when trying to capture complex phenomena. Although the distinction between impairment and disability is helpful conceptually, biomedical and social models also tend to overgeneralize their relationship. Biomedical models suggest that impairment and disability are always coextensive, but if that were true, we should not expect such vast differences in how people with the same impairment are disabled in different contexts. Social models suggest that impairment and disability are completely distinct; according to extreme social models, people with impairments would not be disabled at all in a perfectly just society. Given the heterogeneity of impairments and illnesses, this suggestion is implausible. Some impairments are associated with problematic limitations and pain, regardless of the environment.
Additionally, both sets of models err in how they interpret appropriate accommodation and responsibility. According to biomedical models, patients are responsible for seeking medical interventions, and society is responsible for facilitating access to those medical resources. According to social models, the larger society and institutions are responsible for eliminating ableist barriers in the environment of persons with disabilities. But we should expect that individuals with disabilities will need a plethora of accommodations and forms of assistance, and any simplified response will prove to be inadequate. Some medical interventions could significantly diminish how disabled someone is by her impairment; that same individual could be much less disabled if her surrounding society were not structured according to able-bodied and able-minded norms. The evaluative function of disability models should therefore be more fine-grained than what we find in biomedical and social models. Even Christopher Boorse, who is one of the leading proponents of extreme biomedical models of disability and illness, recently admits that “there is no intrinsic value in normality […] pathology is occasionally preferable to health, and, for almost any disease [or impairment], one can imagine a special environment where it is advantageous.”139 Neither the biomedical model nor the social model can capture the array of contextual considerations that could be relevant in assessing the meaning of disability.

In this section, I will first describe the existing attempts at constructing biopsychosocial models. There are numerous critiques against these models, and disability activists and users/survivors have not generally accepted them. I then analyze how users/survivors would model psychiatric disability, based on what their activists and scholars have said on the topic. Although most users/survivors do not embrace antipsychiatry’s social constructionist view of

139 Boorse, “Disability and Medical Theory” 77
mental illness anymore, they have not offered a model in its stead. I propose a hybrid model that takes into account the multifaceted and variable nature of psychiatric conditions.

**A Growing Spectrum**

Increasingly, disability theorists have sought less extreme models than standard biomedical and social models. Steven Smith provides the below chart to illustrate a fuller spectrum of models:  

<table>
<thead>
<tr>
<th>Medical/Biological Models</th>
<th>Social Models</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. full-essentialist individual deficiency interpretation (FEID)</strong></td>
<td><strong>3. politics of disablement interpretation (POD)</strong></td>
</tr>
<tr>
<td>Disability is caused by fixed medical characteristics that inevitably prelude a life of deficiency and ‘abnormality.’</td>
<td>Disability is caused by social practices that systematically exclude impaired people from the activities of ‘normal citizenship.’</td>
</tr>
<tr>
<td><strong>2. part-essentialist individual deficiency interpretation (PEID)</strong></td>
<td><strong>4. social construction of disablement interpretation (SCOD)</strong></td>
</tr>
<tr>
<td>Whilst disability is caused by the above medical characteristics, these can be partially alleviated by changes in the social environment, so as to enable some degree of ‘normal living.’</td>
<td>Disability is caused by the way impairments are defined and associated with characteristics that are necessarily assumed to have a negative impact on personal identity, development, and fulfillment.</td>
</tr>
</tbody>
</table>

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140 Recreated from Smith, “Social Justice and Disability” 22
Based on Smith’s spectrum, biopsychosocial models (similar to PEID or POD in the above table) acknowledge the contextual features of disability. But unlike the more extreme social models, the POD model still emphasizes independent living.\textsuperscript{141} On this account, normalization and the attainment of valued social roles would be possible if proper accommodations, environmental modifications, and accessibility were made available to individuals with disabilities.\textsuperscript{142} Based on Smith’s description of models like POD, these models reject standard biomedical models’ characterization of disability identity and their explanatory story, but these models do \textit{not} wholly reject the evaluative dimension of biomedical models. In other words, standards for flourishing and agency (e.g., independence) still revolve around able-bodied and able-minded norms.\textsuperscript{143}

An example of the PEID model is evident in the WHO’s more recent theorizing on disability.\textsuperscript{144} Partly in response to objections by disability activists, the WHO compiled the \textit{International Classification of Functioning, Disability and Health} (ICF) in 2002. The WHO describes the ICF as a biopsychosocial model, since it strives to weave together biomedical and social models:

Disability is a complex phenomena \textit{[sic]} that is both a problem at the level of the person’s body, and a complex and primarily social phenomena \textit{[sic]}. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external.\textsuperscript{145}

\textsuperscript{141} Ibid. 18-19. Although Smith puts forward this spectrum, he ultimately supports the SCOD model.
\textsuperscript{142} This view of normalization fits with Wolf Wolfensberger’s conception of it. For comparisons of different normalization principles, see Parmenter 277.
\textsuperscript{143} Smith, “Social Justice and Disability 19-21
\textsuperscript{144} Ibid. 17.
\textsuperscript{145} World Health Organization, \textit{Toward a Common Language} 9
With the ICF, the WHO tries to recognize the importance of internal and external factors, which would also mean that assisting individuals with disabilities should address both sets of factors. However, the ICF has not been embraced by many disability scholars and activists. Michael Oliver and Colin Barnes remark that the ICF’s approach “is not that far removed from its original formulation [in the ICIDH] in that it retains the individual as the starting point for the analysis of bodily function and activity,” and obstacles to equal participation are attributed more to “personal factors” than to social and political structures.\textsuperscript{146} A more successful biopsychosocial model would not start the causal story with factors that are internal to the individual, and it would acknowledge the social, political, and cultural forces that can make all the difference for which limitations and losses someone experiences.

There are biopsychosocial models for psychiatric disabilities as well. The term ‘biopsychosocial’ arose as early as 1954 in modeling discussions, and it grew in popularity as a guiding framework in the 1980s—around the time of the \textit{DSM-III} and psychopharmacology.\textsuperscript{147} In the existing literature, support for biopsychosocial models is based in two notions: 1) the idea that “‘more is better’: truth is achieved by adding more and more perspectives, getting closer and closer to a highly complex reality”, and 2) “medications and psychotherapy are always, and inherently, more effective than either alone.”\textsuperscript{148} This second reason for choosing biopsychosocial models over their competitors is problematic, for it mischaracterizes other models. Specifically, biomedical models do not necessarily rule out psychotherapy as a potentially beneficial intervention. As long as psychotherapy is ultimately meant to affect biological factors, directly or

\textsuperscript{146} Oliver & Barnes 26
\textsuperscript{147} Ghaemi 3
\textsuperscript{148} Ibid. 4.
indirectly, a mental health professional who accepts biomedical modeling can consistently recommend it. Thus, biomedical models of psychiatric disabilities could end up coopting biopsychosocial models; that is, these models could end up looking indistinguishable. If biopsychosocial models are to function better than its competitors, they need further development.

**The Search for a Model in the Psychiatric User/Survivor Movement**

We can see parallels in biomedical and social modeling of psychiatric disability. Biomedical models interpret mental illness as disorders of the brain; “some discreet molecular unit or biological process can be pinpointed […] as the causal entity.” According to these models, psychiatric disability necessarily threatens quality of life. Mental health professionals can best treat these patients with medications and therapies that address the underlying biological problems. Psychotropic medications, electroconvulsive therapy, and other interventions would be intended to alter neural pathways, biochemistry, or other aspects of the brain’s functioning (over time if not immediately). Psychiatry’s reliance on the biomedical model has received numerous critiques. The National Institute of Mental Health (NIMH) has their own manual, the Research Domain Criteria, in which mental illness is exclusively interpreted via the biomedical model. A recent criticism of NIMH summarizes the concern: “[s]elf-reports’ will also apparently be a ‘unit of analysis,’ though interest in the thoughts and testaments of patients seems

149 Thachuk 145
150 See esp. Barnes & Shardlow; Lindow; Chamberlin 12.
characteristically small. The agency’s overwhelming focus is to remain on the brain as the alleged seat and cause of psychiatric suffering.”

Users/survivors’ objections to biomedical modeling are similar to the objections that come out of disability rights activism. The causal story explaining disability is oversimplified by reducing everything about these conditions to the brain, and the environmental context of these disabilities is overlooked. Further, the case against biomedical modeling of psychiatric disability is strengthened by the controversial nature of many psychiatric diagnoses. The *Diagnostic and Statistics Manual of Mental Disorders*, which is the primary diagnostic guide for mental health professionals in the United States, has been heavily criticized throughout the decades by mental health professionals, scholars from a variety of disciplines, and users/survivors for being biased and not sufficiently scientific. Moreover, historically and even currently, the *DSM* has diagnostic categories that are considered prejudicial and tied to the particular sociocultural context of its authors. In other words, the methods for diagnosing psychiatric impairment are thought to be less about biology and more about problematic sociocultural biases of the time.

Antipsychiatry activists prefer models on the opposite side of the spectrum: social constructionist views. Biological anomalies or dysfunctions do not cause mental illness on this model; rather, the so-called “symptoms” associated with psychiatric disabilities are solely caused by the sociocultural and political context, labeling the behaviors and mental states as disorders.

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151 Lane n.pg.
152 See, e.g., Kirk & Kutchins; Caplan, Paula; Linder. Controversial historical examples include Ego-Dystonic Homosexuality (*DSM-III* and *DSM-III-R*), Transsexualism (*DSM-III-R*), Gender Identity Disorder (*DSM-IV-TR*), and Self-Defeating Personality Disorder (*DSM-III-R*, problematic for being almost exclusively applied to women who stayed in abusive relationships). In the current manual, *DSM-V*, controversial diagnoses include Premenstrual Dysphoric Disorder, Transvestic Fetishism, and Gender Dysphoria (though this latter diagnosis was an attempt by the APA to legitimate transgender persons).
and treating the behavior as abnormal.\textsuperscript{153} In the more recent evolution of the user/survivor movement, there has been a push against social constructionism. Many user/survivor groups have distanced themselves from their antipsychiatry roots, since “the blanket condemnation of psychiatric intervention and the determination to portray all mental disorders as social constructs, led their work into disrepute.”\textsuperscript{154} As was mentioned in the last chapter, many users/survivors accept that medical interventions aimed at biological processes (e.g., psychotropic medication) could be beneficial for some patients. They still argue, though, that medical interventions should not be the only available form of accommodation or assistance. Users/survivors have offered no clear alternative to extreme biomedical models or social constructionist models of psychiatric disabilities.

\textit{Interactionist Models of Psychiatric Disability}

I defend an interactionist model of psychiatric disability, which can advance some of the aims of users/survivors.\textsuperscript{155} An interactionist model is a type of biopsychosocial model.\textsuperscript{156} Biopsychosocial models incorporate a multitude of variables in its complex portrayal of disability, but not all of these models focus on the relationship among those variables. For example, the WHO’s revised model (ICF) is biopsychosocial in that it accounts for biological and sociocultural factors in the existence of disability, but it still stresses the causal importance

\textsuperscript{153} Discussed in Caplan, Paula; Szasz 24-25; Hacking 27; Morrison.
\textsuperscript{154} Mulvany 583
\textsuperscript{155} The interactionist model that I propose here had its beginnings in a paper I co-authored with Elizabeth Victor in \textit{The International Journal of Feminist Approaches to Bioethics}. I am grateful to my co-author and to reviewers for their assistance in the early development of this view.
\textsuperscript{156} There is philosophical work to be done on different types of biopsychosocial models, which I do not have the space to develop here.
of biological variables over others. The ICF model does not offer much analysis of how different contributing factors relate to one another. An interactionist model focuses on the interactive relationship among these different variables. I will go through the who/what, why, and evaluative functions of an interactionist model as applied to psychiatric disability.

Interactionist models acknowledge the complex and dynamic features of psychiatric conditions. The biological and environmental features of disability are not completely isolatable. How someone experiences her body will partly depend on her situatedness in a particular environment; likewise, how she experiences her environment will be partly influenced by the features of her embodiment. Wendell makes a similar argument:

> the distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability. They are interactive not only in that complex interactions of social factors and our bodies affect health and functioning, but also in that social arrangements can make a biological condition more or less relevant to almost any situation.\(^{157}\)

As Wendell points out, the interactions among internal and external factors will be fluid, making some features of impairment and disability more prominent than others at different times. There is a concern with interpreting impairment as a given, as if it is a fixed and objective biological state. Jackie Leach Scully argues that the “marginalization of disabled people cannot be effectively tackled, either theoretically or politically, if the subjective experience of impairment is left out.”\(^{158}\) Disability models should move away from the historical separation of impairment and disability as if the former is fixed and only the latter is contextual, a concern increasingly

\(^{157}\) Wendell 35
\(^{158}\) Scully, *Disability Bioethics* 29
raised by disability studies scholars. On an interactionist model, impairment and disability are closely intertwined and fluid concepts, and context matters for understanding the biological and the environmental features of both. Because of its nuanced and contextual interpretation of disability, interactionist modeling avoids over-generalizing these conditions as if they are homogenous—a pitfall not uncommon to biomedical and social models.

When the interaction of biological and environmental factors is central to the analysis of disability, then the explanatory story for disability will be complex and dynamic. Instead of a particular set of factors being attributed as the sole or primary cause, the relationship between these factors is the focus of analysis. In the case of psychiatric disability, there is evidence that environmental factors can affect which neural pathways and biochemical patterns emerge. Diane Halpern shows that “[e]ven hormones, which are usually considered biological variables, do not act in fixed or preprogrammed ways, but act within a context.” Contextual factors can directly or indirectly inform biological processes, which means that many of the biological factors underlying impairments can be sensitive to environmental conditions.

This model suggests that most people who qualify for psychiatric disability will have a combination of factors that feed into and reinforce one another; this does not mean, however, that all of the causes will be equally observable or testable at any given point in time, since interactions can take different forms. Especially for framing psychiatric impairment, it is commonly believed that “turning away from monocausal attempts at an explanation is based on

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159 Tom Shakespeare, Anita Silvers, Jenny Morris, Sally French, Julie Mulvany, and Liz Crow have all raised this concern about extreme social models that rely on a sharp contrast between impairment and disability.

160 Halpern, Diane 116
the fact that neither paradigm [strictly biomedical or strictly social] was able to gain exclusive acceptance by scientists and practitioners.”161 A complex explanatory story more accurately and precisely captures the intricacy of how the brain functions and how it affects the individual.

In addition, the causal story can incorporate the interaction of factors in the labeling of mental illness. Due to the stigma and common misperceptions about psychiatric disabilities, being labeled as mentally ill can affect how these individuals are perceived, how they function, what they imagine as possible for themselves, and which behavior is expectable. Ian Hacking describes interactive kinds as those things that interact with their classification; the actions of the labeled and the actions of others toward the labeled persons result in a looping effect between the label and the classification itself. Whereas Pluto is an indifferent kind because it does not interact in any way with its classification, the label of ‘feeble-minded’ and ‘insane’ can be interactive.162 As a result of this feedback loop, the features of emotions and behaviors (what are considered symptoms) can be responsive to the individual’s being labeled as mentally disordered, which in turn can trigger certain biological responses. In response to the “why” question, therefore, the interactionist model focuses on the relationship among a plethora of factors instead of attributing disability primarily to biological or social factors alone.

On interactionist models, disability identities are not necessarily negative or positive. Because of their dynamic nature, disabilities can change over time, which is especially evident with psychiatric conditions. For example, an individual with schizophrenia could view her identity as an empowered and gifted one because of how she values her disabled mode of being.

161 Richter 21
162 Hacking 103-124
At this time, she might have the requisite capacities to claim an identity – to have an enduring sense of self over time and to appreciate aspects of her self-conception. She could be capable of understanding the interaction of variables underlying her disability, and she could grasp the ways in which her psychiatric condition affects her life.\footnote{163} All of this could change, however, depending on what happens biologically and environmentally. She could become decompensated, losing the above-mentioned capacities. Her schizophrenia could become more profound, leading to a lost sense of enduring self. In this situation, her disability identity is fragmented and not the positive one it used to be for her. Identities associated with psychiatric disabilities are not always ones of suffering and tragedy, either. Julie Mulvany points out that “the tendency to conceptualise ‘mental patients’ as an undifferentiated group of victims restricts the potential […] to both analyse and support the interests of the developing mental health consumer movement.”\footnote{164}

In regard to its evaluative function, an interactionist model would incorporate values and expertise from multiple angles. These models have the virtue of neutrality in how it conceptualizes psychiatric conditions. As mentioned in the last chapter, Anita Silvers argues that we should have a neutral framework for understanding disabilities, so our model does not “deny that disabilities can be health issues, but instead […] acknowledge[s] they are neither necessarily nor mainly so.”\footnote{165} If a disability model is to help facilitate productive conversations among different stakeholders (such as mental health professionals and users/survivors), then the model

\footnote{163} One could object that individuals with psychiatric impairments are not capable of understanding their condition or how it affects their lives; in clinical terminology, the argument would be that all of these individuals (or at least those with schizophrenia and other psychoses) lack insight. There are both conceptual and empirical reasons for refuting this objection, which I discuss in chapter five.  
\footnote{164} Mulvany 587  
\footnote{165} Silvers, “On the Possibility” 477
should not presume that all impairments are necessarily problematic limitations, and it should not presume the opposite, either. An interactionist model does not presume from the outset that any particular individual with a psychiatric disability is right or wrong in her report about her flourishing potential. An interactionist model does leave conceptual room for the possibility that someone could flourish in virtue of her disability; such a claim is not unintelligible on this model. To determine whether a psychiatric disability diminishes flourishing potential, we need information about biological factors (e.g., their severity and reversibility) and environmental factors (e.g., whether social barriers associated with the label of mental illness have foreclosed the possibility of attaining basic goods), along with how these factors can interact and perpetuate one another.

On an interactionist model, appropriate accommodations for psychiatric disabilities will probably not be a simple matter of physiological treatments (e.g., through pharmaceuticals), nor will it be a simple matter of overhauling oppressive or unjust systems. Neural degeneration and other biological factors associated with psychiatric impairment can cause problematic limitations—regardless of changes to the sociocultural environment. Only addressing social factors will not eliminate disability for individuals whose biological condition threatens basic functioning and agency, which can occur when psychiatric impairments lead to (e.g.) decreased glial density or reduced gray matter in the brain.\textsuperscript{166} Likewise, environmental factors can be so significant for some psychiatric disabilities that biological treatments alone would never be able

\textsuperscript{166} Preliminary studies reveal “structural abnormalities in the prefrontal and dorsal lateral cortexes of person with untreated bipolar and other mood disorders, including cortical thinning, the reduction of gray matter in these regions, and various cell pathologies including alternation in neuronal and glial density” (Epright 804). These alterations can lead to permanent losses that are essential to agency and thinking capacities.
to eliminate the disabilities. Since biological features, environmental triggers, and the labeling of mental illness coalesce in causing disability, all of these factors will be relevant when providing assistance for individuals with these conditions. Which form of assistance is *most* needed will depend on which contributing factors are the most pronounced at the time.

**IMPLICATIONS OF INTERACTIONIST MODELING FOR THE USER/SURVIVOR MOVEMENT**

How psychiatric disability is modeled makes a significant difference for how users/survivors’ perspectives are understood, interpreted, and accommodated. Interactionist models cover a large variety of perspectives and experiences of disability. They can accommodate many of the claims made by users/survivors, but they do not lose track of how mental health professionals can reasonably and respectfully assist patients. Because interactionist models provide a more accurate and precise picture of psychiatric conditions than the alternatives, and because they accommodate some of the central claims of users/survivors, this type of model holds the most hope for supporting their activist aims.

Although users/survivors historically embraced social constructionist views of psychiatric conditions, these views are problematic for several reasons. Social constructionist models suggest that medical interventions should not be attempted for patients with psychiatric diagnoses, since the only problem is the labeling of behaviors as disordered and treating them as such. This view of psychiatric disability will not be plausible or compelling except to those who buy into antipsychiatry. As long as users/survivors cling onto social constructionist models, therefore, they are alienating potential allies. Their claims could receive more traction if they did

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not adopt a model that basically denies the existence of psychiatric impairments. If users/survivors acknowledge that biological factors can cause problematic limitations in certain cases, then they could have a more receptive audience for their activism. Social constructionist models do not fit with how the user/survivor movement has evolved, anyway; since so many groups accept that certain medical interventions could be beneficial, including psychotropic medications, they are no longer in agreement with the extreme views of Thomas Szasz and R.D. Laing.

In it causal explanations and evaluative functioning, disability models should not hedge out expertise that speaks to the lived experiences of disability. They should reflect proper neutrality and humility when it comes to how disability and impairment can be perceived and valued (or not) by individuals who have vastly different experiences with these conditions. Interactionist models accomplish these aims better than the alternatives. This type of model is not pre-loaded with assumptions that always favor viewing psychiatric disability as a form of generative madness on the one side or as tragic instability on the other. While interactionist models allow for the possibility that psychiatric disabilities could diminish flourishing potential and even harm agency, they also allow for the possibility that a psychiatric disability could be associated with a positive identity and a mode of being with high flourishing potential. When users/survivors claim to flourish in virtue of their psychiatric disabilities, this claim is intelligible and potentially accurate on interactionist modeling. The next chapter analyzes users/survivors’ demands for recognition of this claimed mental diversity. In chapter four, I delve into this claim further, and I argue that some psychiatrically disabled modes of being could contribute to

167 I explain the notion of generative madness in chapters one and five.
meaningful living, which means there are prima facie obligations to respect them. The notion of mental diversity is able to get off the ground in this dissertation because psychiatric conditions are modeled as complex and dynamic disabilities that are not necessarily tragic or undesirable.

By having the appropriate model in place for clinical practice, the combined expertise of patients and clinicians will be significant for understanding the nature of the disability and appropriate interventions. Because of the importance of contextual details in interactionist modeling, notions of recovery can be fine-grained and tailored to the individual. Thus, “the question of interest is not what a group of people would benefit from, but rather what this individual would benefit from.”¹⁶⁸ What constitutes recovery would be based on the particular interaction of variables in any given case, which does not mean that recovery is purely subjective and dictated by the patient. As a normative guide for the therapeutic relationship, “[s]hared decision making assumes that there are two experts in the relationship—client and practitioner.”¹⁶⁹ Shared decision-making can move from an ideal to an actuality for this group of patients if their narratives are better integrated in the understanding of psychiatric disability. In chapter five, I argue that shared decision-making can be possible even in a number of difficult cases, such as when the patient and health care professional initially disagree on what “getting better” means for the individual patient. The therapeutic relationship will struggle if the patient and health care professional adopt opposing disability models, but interactionist modeling facilitates collaboration and does not overlook critical evidence from either party.

¹⁶⁸ Slade 82, emphasis added
¹⁶⁹ Kirkpatrick 63
CHAPTER THREE: RECOGNITION OF MENTAL DIVERSITY ¹⁷⁰

As has been detailed in the previous chapters, the psychiatric user/survivor movement aims to give voice to the specific needs, interests, and perspectives of individuals with psychiatric disabilities.¹⁷¹ Users/survivors contend that their knowledge claims are routinely diminished or ignored and that individuals with psychiatric diagnoses are too often denied a sufficient level of participation in decision-making. As a result, this population experiences what is known as systemic misrecognition. Individuals with actual or suspected psychiatric disabilities are susceptible to the harm of misrecognition in their everyday interactions, as well as in larger policies and practices, such as in health care institutions. Users/survivors want recognition for their “mental diversity,” which includes “unusual (some call them ‘spectacular’) ways of processing information and emotion.”¹⁷²

Demands for recognition arise when groups have been marginalized, resulting in the subjugation of their distinctive viewpoints. Iris Marion Young explains that marginalization “is perhaps the most dangerous form of oppression” because a “whole category of people is expelled from useful participation in social life.”¹⁷³ Marginalization can result from policies intended to denigrate and segregate populations, but it can also result from preemptive paternalism and implicit biases. Misrecognition results in and is perpetuated by marginalization. When a group experiences misrecognition, they struggle against pressures to conform to socially expected roles

¹⁷⁰ I presented an earlier version of this paper at a National Endowment for the Humanities Bioethics Colloquium hosted by Hood College in Spring 2014. I am grateful to Katy Fulfer and the attendees for their thoughtful comments and questions.
¹⁷¹ As I have noted previously, not all individuals with psychiatric disabilities would agree with the aims of users/survivors. My analysis focuses on users/survivors and those they do represent.
¹⁷² Quart n.pg.
¹⁷³ Young, “Fives Faces of Oppression” 53
or norms, and their claims of valuable difference do not receive the acknowledgement that the group believes they deserve. Individuals with psychiatric disabilities are regularly subjected to pressures to accept traditional mental health norms and to *recover from* their condition with professional help if necessary. When someone with a psychiatric disability defies these expectations and instead wants respect for her disabled mode of being, she will likely meet both skepticism and paternalism.

To clarify the duties of recognition that are salient for individuals with psychiatric disabilities who are represented by users/survivors, I first provide philosophical background on recognition politics as it pertains to public and private spheres. The public sphere incorporates laws, polices, and institutional structures. The private sphere is made up of interpersonal interactions, such as those that occur in intimate relationships and encounters with health care professionals. The work of Axel Honneth, Charles Taylor, Iris Marion Young, Nancy Fraser, and Heikki Ikäheimo show the different dimensions of recognition politics. Although there are important debates among these philosophers (that are outside the scope of this dissertation), together they illustrate the importance of accommodating and respecting the interests of marginalized groups in different areas of their lives. There is near silence\(^{174}\) in the literature on recognition politics in relation to user/survivor activism, so this foundational philosophical work will help guide my analysis.

Achieving recognition for users/survivors will have distinctive philosophical challenges. Their claimed identities and modes of being are scrutinized as pathological and in need of fixing,

\(^{174}\) I am not the first to bring together user/survivor activism and recognition politics, as Sara Goering and Jennifer Radden have publications on this topic, and their ideas will appear later in this chapter.
which means that users/survivors’ claimed form of valuable diversity does not have the same perceived moral pull as when those claims come from other groups. Psychiatric disability, as a condition, can threaten epistemic standing and capacities to value. Duties of recognition are limited; they do not apply in all possible cases of difference. Deafness, by way of contrast, does not similarly threaten someone’s agency. I analyze some of the central challenges that users/survivors face in achieving recognition for mental diversity. I argue that these barriers to recognition can be overcome, though duties of recognition will not apply in all cases of psychiatric disability.

I then demonstrate how philosophical views of recognition relate to prominent social justice movements. This investigation should help illuminate the meaning and implications of recognition, so the philosophical foundations are enhanced with more concrete examples. Some of these other marginalized groups have similar experiences and concerns as many individuals with psychiatric disabilities, so their demands for recognition will resonate for users/survivors. I discuss demands for recognition coming from cultural, ethnic, and racial minorities, disability rights activists, the Deaf Gain community, and the neurodiversity movement.175 By surveying the recognition politics of these other groups, I can better analyze what this struggle means for users/survivors, even though mental diversity is importantly different from other forms of diversity. I reference these other groups’ demands for recognition while refining what the demands should be for users/survivors.

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175 I do not mean to imply that any of these groups are homogenous. There can be variations in how recognition is conceptualized, pursued, and prioritized (or not) by any subgroup or individual within these larger social groups.
Recognition politics brings to light the narratives of the marginalized individuals in the group. To get a better foothold on what recognition could specifically mean for users/survivors, I analyze some of the first-person perspectives coming from these activists. Their narratives suggest that individuals with psychiatric disabilities often have unique epistemic access to their lived condition, and their personal narratives challenge dominant cultural narratives about the meaning and experience of psychiatric disability. These narratives reveal what users/survivors want in terms of recognition, as well as how they view mental diversity. My focus is on those cases when duties of recognition do apply, but they are mistakenly neglected.

PHILOSOPHICAL UNDERPINNINGS OF RECOGNITION POLITICS

Recognition, as a moral and political aim, involves more than mere *acknowledgement* of difference; rather, recognition requires accommodating differences based on the group’s self-identified needs and interests. Otherwise, differences among groups could receive accommodation according to outsiders’ judgments about what their needs are. Respect for first-person narratives and more than tokenistic participation are demanded. Recognition necessitates a certain form of regard, and this type of regard has restorative potential in that it can go some way toward rectifying current and past injustices.

The call for recognition comes as a result of a group experiencing systematic, institutionalized, and long-standing marginalization. The individuals in this group are treated as Other or as lesser-than or as borderline persons. Instead of having their perspectives appreciated and their distinctive traits as *individuals* taken seriously, they are vulnerable to degrading
stereotypes and misperceptions. Calls for recognition unify many social justice movements, such as those representing cultural minorities and individuals with disabilities. Struggles for recognition, in the philosophical tradition of Axel Honneth, “are social processes in which certain groups in society contest the predominant and, in their eyes, demeaning social standards of expectation and evaluation that ascribe to different members of society certain ‘appropriate’ roles, statuses, or characteristics” that have implications for public treatment (such as in forced assimilation in educational systems) and for private treatment (such as in sexist interactions encouraged by socially accepted etiquette). I will provide a brief overview of how philosophers have imagined recognition at the policy or institutional level and at the more intimate or interpersonal level.

Recognition in the Public Sphere

When marginalized groups demand recognition, they view justice as extending beyond the fair (re)distribution of material goods. According to Iris Marion Young, the “idea of justice here shifts from a locus on distributive patterns to procedural issues of participation in deliberation and decisionmaking. […] for a social condition to be just, it must enable all to meet their needs and exercise their freedom; thus justice requires that all be able to express their needs.” The politics of equal recognition could have different meanings based on how this shift in justice is understood. On the one hand, it could lead to a politics of universalism that exalts the dignity of all individuals, regardless of socioeconomic status or political power.

176 van den Brink & Owen 2
177 Young, Justice and the Politics of Difference 34
Alternatively, it could amount to a *politics of difference* that focuses on distinctions among individual groups and persons and how these differences call for different rights, entitlements, or protections.\(^{178}\) Charles Taylor argues that the politics of universalism was historically needed to establish that everyone deserves respect, but the politics of difference helps to emphasize that what is respect-worthy is universal human potential, which is the “potential for forming and defining one’s own identity.”\(^{179}\) In other words, the politics of difference tries to protect individuals in their pursuits to become who they want to be – even when contrary to the prevailing cultures or dominant conceptions of the good life.

Justice, on this account, needs to address the myriad of ways in which group difference and individual perspectives can be subjugated and marginalized across institutional and social spheres. Taylor argues that the principle of fairness requires that people be able to cultivate their own distinctive identities; recognition of difference requires “recognizing the equal value of different ways of being.”\(^{180}\) In other words, a just society will ensure the material and social conditions necessary for individuals to build and maintain their distinctive identities, and these identities should be given appropriate uptake as legitimate, authentic, and more valuable than modes of being that are imposed or forced externally from outsiders.\(^{181}\) Greater participation and inclusion can best be achieved, Young argues, by supporting difference rather than pushing for assimilation.\(^{182}\) A key question is how to establish the conditions necessary to accomplish the aim of recognition. A detailed answer to this question must be specific to the historical

\(^{178}\) Taylor, “The Politics of Recognition” 38  
\(^{179}\) Ibid. 42  
\(^{180}\) Taylor, *The Ethics of Authenticity* 51  
\(^{181}\) Taylor’s communitarian critique of liberalism and his argument for special rights of minority groups are not directly relevant to my discussion, so I will not delve into his larger framework and argument.  
\(^{182}\) Young, *Justice and the Politics of Difference* 171
circumstances and particular challenges faced by the group, and individuals within the group could vary in which forms of misrecognition they encounter in different contexts.

Difference, as a value for social justice, would no longer designate Otherness; “[b]y asserting a positive meaning for their own identity, oppressed groups seek to seize the power of naming difference itself, and explode the implicit definition of difference as deviance in relation to a norm.”

Ideally, a society would enable group empowerment without pigeonholing the identity of the group based on cultural narrative, incorporate insights and perspectives from a variety of individuals within the group, and permit those within the group to give feedback on the deliberation. Young asserts that “a democratic public should provide mechanisms for the effective recognition and representation of the distinct voices and perspectives of those of its constituent groups that are oppressed or disadvantaged.” Whenever there are decisions related to law, policy, funding, research, or institutional/political structures, duties of recognition would involve finding or creating opportunities for partnership with those affected by these decisions—even if they are not in the majority and even if their perspectives challenge the majority.

The crux of the concern, as Charles Taylor puts it, is that social groups with less privilege or power than the dominant group(s) are faced with either assimilating into cultural identities that they would not otherwise choose to embrace or having their distinctive identities rendered invisible or distorted within the prevailing cultural narrative. How this dilemma plays out in the specific lives of individuals will be complex and not necessarily easy to trace, especially since

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183 Ibid.
184 Ibid.
185 Ibid. 184.
social identities are not monolithic or easily isolatable. This dilemma should nonetheless be expected when certain groups (however defined) claim they are denied opportunities to develop their own modes of being according to their own values. In such cases, the concern is that group and individual differences have been “ignored, glossed over, assimilated to a dominant or majority identity,” which is “the cardinal sin against the ideal of authenticity.”

Nancy Fraser argues that what needs to be recognized is the status of individual group members as equal participants in social life. According to Fraser, the loss of this status is not from isolated experiences of ill will or domination on the part of individuals; rather, when “institutionalized patterns of cultural value constitute some actors as inferior, excluded, wholly other or simply invisible, hence as less than full partners in social interaction, then we should speak of misrecognition and status subordination.” For Fraser, recognition does not require an essentialized group identity on the part of the claimants. The point is to identify and ameliorate shared experiences of marginalization. Therefore, demands for recognition are aimed at “deinstitutionalizing patterns of cultural value that impede parity of participation and replacing them with patterns that foster it”. As a result of this denial of participatory parity (a term of

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186 What constitutes a social group and how these forms over time are outside the scope of this project.
187 Taylor, “The Politics of Recognition” 38
188 She contends that misrecognition should not be viewed first and foremost as a threat to identity, since doing so “abstracts the injustice from its institutional matrix and obscures its entwinement with economic inequality;” additionally, an identity-focused approach to recognition “essentialises identity, pressuring individual members to conform, denying the complexity of their lives, the multiplicity of their identifications, and the cross-pulls of their various affiliations” (“Why Overcoming Prejudice Is Not Enough” 23). There is philosophical disagreement on whether misrecognition or maldistribution is more morally urgent or whether projects to ameliorate these two issues are intertwined. Iris Marion Young is among Fraser’s more vocal critics (see Scully, Disability Bioethics 135 for more on this particular philosophical dispute). I do not attempt to resolve the philosophical disagreements among Taylor, Young, Fraser, and Rorty. Different social justice movements, as illustrated in a later section of this chapter, vary in what they prioritize in their calls for recognition.
189 Fraser, “Recognition without Ethics?” 24
190 Fraser, “Why Overcoming Prejudice Is Not Enough” 24, italics removed
Fraser’s), the distinctive characteristics of these groups are lost within the larger dominant culture. These individuals then struggle to assert their freedoms to self-define and to pursue their distinctive conception of the good life.\(^{191}\)

**Recognition in the Private Sphere\(^{192}\)**

The interpersonal and institutional dimensions of recognition have a common basis. At the interpersonal level, a lack of recognition significantly affects someone’s ability to interact with others as an equal member of a community. Heikki Ikäheimo argues that “to the extent that you are not an object of their recognitive attitudes and thus not included interpersonally *with the interpersonal standing or status of a person*, in a very important sense you are still socially excluded.”\(^{193}\) An implication of this view is that recognition involves more than merely soliciting the input of marginalized individuals, since doing so could run the risk of treating persons only as research subjects or data points.

Axel Honneth elaborates on what interpersonal recognition involves. He argues that there are different modes of recognition that revolve around emotional support, cognitive respect, and

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191 Fraser, “Recognition without Ethics?” 27
192 Michael Seymour recently argues that demands for recognition can raise issues of justice only if they do not fall into psychologism—that is, “the concept of recognition must not be construed as a strictly psychological notion and be confined only to the interactions that take place between individuals. Just as we distinguish between tolerance as a psychological attitude and the political principle of toleration, we should also distinguish between recognition as a psychological attitude and the various approaches to the politics of recognition, understood as a set of institutional measures designed to accommodate persons and peoples” (228-229). Although I agree with Seymour that the concept of recognition should not be restricted to interactions between individuals and merely focused on attitudes, I think it is a mistake to suggest that the interpersonal is outside the scope of recognition politics. Even if there are institutional mechanisms in place to accommodate minority groups, those mechanisms will not adequately minimize lack of access and lack of participatory parity if there is exclusion and dismissal at the interpersonal level. Feminist activists and scholars have made the point succinctly: The personal is political. I expand on these points in this section and later sections.
193 Ikäheimo 86
social esteem. Because of our social embeddedness, we rely on others to show us that we are worthy of this care, respect, and esteem; otherwise, on self-reflection, we would struggle to see our distinctive traits as worthy of anything besides denigration and dismissal. Interpersonal interactions have a significant formative effect on how we view ourselves and how others come to view us as social partners. Honneth remarks, “to esteem one another symmetrically means to view one another in light of values that allow the abilities and traits of the other to appear significant for shared praxis […] For only to the degree to which I actively care about the development of the other’s characteristics (which seem foreign to me) can our shared goals be realized.” For Honneth, relations of recognition allow for social solidarity in common causes. Misrecognition threatens individuals’ sense of their own agency, which makes it more difficult to form affiliative bonds with others.

Following the philosophical tradition of Honneth, Taylor argues that intimate relationships demonstrate to us that we are worthy of respect and inclusion instead of derision and exclusion. With interpersonal misrecognition, as with internalized oppression, “a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves […] imprisoning someone in a false, distorted, and reduced mode of being.” Taylor emphasizes the dialogic nature of our sense of self; it is through our interactions with others that we develop and maintain our identities and modes of being throughout our lives. What we learn about our standing in the private sphere can affect how we view our standing in the public sphere: Should

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194 Honneth 129
195 Taylor 1994, 25
we feel confident in asserting ourselves in public contexts, making demands and asking for participatory roles? Do we have anything meaningful to contribute, based on our knowledge and expertise? The answers to these questions can, to a large extent, depend on what we have discovered in our interpersonal encounters. While our most intimate relationships will have a crucial impact on our sense of respect, relationships with others (such as clinicians) can become similarly intimate if they influence our sense of self at this most fundamental level. Establishing the conditions necessary for public recognition would mean very little without this interpersonal dimension. Marginalized agents need relationships that allow them the necessary safety to develop who they are and pursue modes of being that are of value to them based on their own self-understanding.

DISTINCTIVE CHALLENGES FOR USERS/SURVIVORS ACHIEVING RECOGNITION

I will identify three main barriers that psychiatric users/survivors face in having their demands for recognition receive uptake from others. These interrelated but separate barriers all take the form of increased scrutiny in regard to a) their agential standing, b) their epistemic standing, and c) any claims made about valuable aspects of mental diversity. For each of these, I will provide reasons for questioning these barriers, showing that successful recognition claims are possible for this group.
**Agential Standing**

To get clearer on the first barrier, we can separate those elements that are necessary for minimally functional agency and those that constitute ideals of autonomous agency. For the former, basic means-end reasoning, a somewhat stable sense of self over time, some coordination of ends, and minimal coherence and consistence of ends will at least be needed.\(^{196}\) For the latter, we strive for focused and reflective deliberation, the absence of undue influence, some measure of control over our will and actions, and arguably a conviction in our own worth as agents.\(^{197}\) For a group’s recognition politics to get off the ground, they need to be seen as political agents. If the individuals within the group are viewed as diminished in their ability to set ends and achieve meaningful action, then their political claims and activism will be discounted as fly-by-night, potentially frivolous, and without lasting merit.

A diagnosis of psychiatric impairment can cast doubt on whether someone is capable of any of these elements of minimally functional agency or autonomous agency. One of the distinguishing features of psychiatric disability is its fragmenting effects.\(^{198}\) I divide fragmentation into two broad groupings: thought disorders and affective distortions. Thought disorders can involve unconventional methods for gathering and processing information, which can result in unusual connections and seemingly implausible or irrational conclusions. Affective distortions can influence which factors in a situation appear as salient, the individual’s

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\(^{196}\) The components of agents and what counts as *minimally functional* agency are debatable. While some philosophers locate agency in intentional states and reason-giving, others argue that agency can arise spontaneously without intention or reason (Schlosser). What I suggest here is meant to be relatively uncontroversial, capturing the sorts of capacities that a human, non-wanton agent should have.

\(^{197}\) These elements are part of a substantive account of autonomy (see, e.g., Mackenzie & Stoljar; Dworkin, Gerald, *Theory and Practice of Autonomy*).

\(^{198}\) For different analyses of fragmentation and “identity illnesses,” see the following: Radden, “Personal Identity” 141, 143; Roe & Davidson 93; Davidson & Strauss 132-134; Geekie 91; Lauveng 81.
attentiveness and responsiveness to those factors, and the forms of attachment or bonding that are open to her. Fragmentation, when severe, can make someone feel inexplicably but intractably compelled toward certain actions. Fragmentation exists along a spectrum; mentally healthy individuals are not wholly unified\(^{199}\) with ideal rationality, unimpeachable information gathering and processing, and perfectly balanced emotional states. Different degrees and types of fragmentation, however, can compromise capacities that are necessary for agential standing. Given this spectrum of fragmentation, the particulars of the individual’s mental condition and circumstances will make all the difference in how her agential standing should be assessed. Moreover, someone could retain sufficient agential capacities in some decisional contexts and lack sufficient agential capacities in others. There is a danger is blanket labeling all individuals with psychiatric disabilities as completely lacking agency; dismissing recognition claims for all of them on this basis overlooks the vast heterogeneity of this population.

**Epistemic Standing**

Individuals with psychiatric disabilities also frequently have her epistemic standing questioned. As a result of their credibility as knowers being distrusted, individuals who are labeled as mentally ill often have their first-person reports and general testimony dismissed or unsolicited. As Sara Goering points out: “When the impairment in question is one that results in diminished judgment, an in inability to self-reflect accurately, how are we to evaluate claims to misrecognition or mistreatment? Our usual best source of information—the misrecognized

\(^{199}\) Perry 144-145
individual himself—appears unreliable.”

The problem of diminished epistemic standing is a significant one, since demands for recognition can only be given credence if they reflect understanding and appreciation of unjust disadvantages that individuals experience due to affiliation with a social group. Some psychiatric disabilities have such severe fragmentation effects that the individual cannot process information in a way that would lead to reliable knowledge. These individuals would not be capable of making recognition claims, even if they still deserve assistance and access to resources as a matter of justice. But it would be a mistake to presume that all individuals with psychiatric disabilities are in this situation, or that they can only escape this situation if they accept medical treatments.

Another major source of skepticism toward the epistemic standing of individuals with psychiatric disabilities comes from their presumed lack of clinical insight. ‘Clinical insight’ broadly refers to patients’ self-knowledge—that is, their understanding of their medical condition. The question of whether a patient has insight is among the first to be considered in psychiatric contexts, and a determination of poor insight will generally permit considerable paternalistic interferences for the sake of what is presumed to be in the best interests of the patient. As long as poor insight is suspected, claims to patient expertise or self-definition are open to refutation. There are several competing conceptions of insight, and data on which groups of patients tend to lack insight have changed dramatically over the years. For example, some researchers claim that all psychiatric conditions compromise insight; others suggest that

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200 Goering, “‘Mental Illness’ and Justice as Recognition” 16-17
201 Contrast the conceptions put forward by the following: WHO (qtd. in Amador, et al., “Awareness of Illness in Schizophrenia”117); APA DSM IV-TR; Amador & Kronengold; McGorry & McConville; David; Marková & Berrios; Dell’Osso, et al..
202 E.g., cf. Epright, Marková & Berrios, McGorry & McConville, Amador
psychotic conditions are distinct in having poor insight as one of the necessary symptoms.

Several studies find no correlation between level of insight and severity of psychopathology, but others come to the opposite conclusion.\textsuperscript{203}

Some scholars contend that full insight requires the “ability of the individual to effect [sic] the normal transition from looking at oneself from \textit{within} to looking at oneself from the \textit{outside}, by the eyes of the world."\textsuperscript{204} On this account, insight requires taking on an outsider’s epistemic position towards one’s own lived experiences. If the patient’s insider perspective is dismissed entirely, then a failure of recognition has occurred. The clinical, scientific understanding of the illness would be the only interpretation that matters. But to be respectful and cognizant of the numerous ways in which an illness can manifest and affect a person, first-person reports from these individuals need to carry weight. If self-knowledge is reduced to knowledge-of-mental-illness-according-to-standard-medical-textbooks-and-training, then the particularities of the individual’s situation, values, and judgments are being dismissed out-of-hand.\textsuperscript{205}

Distrust of users/survivors’ knowledge claims can furthermore stem from common misperceptions and stigmas against this population. For example, it has been found that a diagnosis of a depressive condition can create a lens through which clinicians view all other medical complaints that a patient makes, potentially resulting in a lower quality of care.\textsuperscript{206} Stigma fuels the false assumption that all people diagnosed with psychiatric impairments are in a

\begin{footnotes}
\item[203] McGorry & McConville 133; Amador 120; Epright 803
\item[204] Marková & Berrios 851
\item[205] Chapter five will delve into the value and limitations of insight determinations as they affect shared decision-making.
\item[206] Thachuk 155
\end{footnotes}
constant state of delusion or that they are cut off from reason. Stigma and stereotype threats work together to suggest that an individual with periodic poor reporting due to psychiatric impairment is now in a lower class altogether as a knower—without taking into consideration that not all episodes lead to the same epistemic vantage point for the individual. In other words, although psychiatric impairment can lead to diminished epistemic standing during certain episodes, the individual could be a reliable knower with certain information at certain times – even perhaps most of the time. Distinguishing when an individual has sufficiently strong epistemic standing to demand recognition will be its own challenge.207

Pervasive epistemic injustice can thwart a group’s attempts at recognition politics before it even begins. Miranda Fricker describes how prejudice arising from negative stereotypes can distort someone’s assessment of an interlocutor’s credibility, which can follow the interlocutor in a wide range of social activities. The result is a form of epistemic injustice, which Fricker calls “testimonial injustice.” The primary harm of such an injustice, Fricker lays out, is to be “wronged as a knower […] to be wronged in a capacity essential to human value.”208 Someone with dubious credibility as an epistemic agent will be degraded as a person; her reports, perspective, and judgments will be dismissed or belittled when they should not be. Fricker argues that testimonial injustice can devalue someone’s epistemic competence, sincerity, or both—thus devaluing her general epistemic trustworthiness. This primary harm has practical effects, since the denial of credibility can hurt someone in a courtroom, in the workplace, and elsewhere.209

207 Goering, “‘Mental Illness’ and Justice as Recognition” 17-18
208 Fricker 44
209 Ibid. 45-46
Fricker identifies a secondary harm of testimonial injustice: “not only is he repeatedly subject to the intrinsic epistemic insult that is the primary injustice, but where this persistent intellectual undermining causes him to lose confidence in his beliefs and/or his justification for them, he literally loses knowledge.”210 The continual doubts from others can be internalized, which means that the victim of this injustice can learn to distrust her own abilities to understand and relay accurate information. This internalization in turn can lead to a general loss of intellectual virtues and intellectual character, since the pursuit of knowledge and standing by one’s convictions will lose their place of importance for someone without epistemic self-trust.211 Negative stereotypes and stigma against this population thus present significant obstacles to having their viewpoint and their self-identified interests and needs respected.

The Value of Mental Diversity

The third significant barrier to recognition for psychiatric users/survivors concerns the nature of their diversity; claims that they are experiencing valuable modes of being in virtue of their psychiatric disability will meet with general suspicion. Even if a person’s agential or epistemic standing has not been overly threatened, she will nonetheless have a hard time convincing the general public that psychiatric difference is a valuable form of difference. Nancy Fraser and others have suggested that mere difference has no intrinsic value.212 What makes a culture, worldview, or mode of being sufficiently valuable to fall under duties of recognition is a

210 Ibid. 49
211 Ibid. 49-50
212 Fraser, “Recognition without Ethics?” 23
philosophically complicated question in itself. This issue is especially tricky in regards to mental diversity. Whereas some variant modes of being can successfully challenge standard notions of what constitutes meaningful living, others will be so fragmented as to paralyze or undermine fundamental components of agency and flourishing. A basic duty of beneficence would grind against the duty of recognition in cases where the psychiatric impairment is severe.

Unlike other forms of diversity that should be protected as a matter of justice, mental diversity is generally presumed not to offer anything valuable for the individual, those within the group, or the larger community. Jennifer Radden explains that “[w]ithin the master narrative, psychotic episodes are at most opportunity costs in a more functional life trajectory, and are no more meaningful than a bad dream.”213 Unlike with other forms of difference that more clearly call for recognition, in the case of psychiatric disability, “the kind of impairment seems to challenge more fully the ‘norm’ of a worker or even a regular citizen. We may be open to multiple modes of functioning (reading text vs. Braille, conversing verbally or with ASL, rolling vs. walking, etc.), but we tend to think that functioning itself takes a certain kind of cognitive capacity and reliability.”214

However, not all modes of being within mental diversity should raise these concerns. For example, voice hearing, hallucinations, and manic creativity do not necessarily put the individual’s life or agency at risk. A recent investigation into delusions and hallucinations found that these phenomena are not always indicative of severe psychosis and can even appear in

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213 Radden, “Recognition Rights” n.pg. Radden defends recognition for users/survivors in the face of this master narrative.
214 Goering, “Mental Illness’ and Justice as Recognition” 15. Goering does not reject recognition claims coming from users/survivors.
“normal,” mentally healthy individuals. It would be a mistake to presume that any benefit, gift, or positive associated with a psychiatric disability is offset by the dangers inherent to the condition. As mentioned in the first chapter, there are common misperceptions about these individuals’ competence, dangerousness, tendency toward violence, and unpredictability. Since these conditions do not usually put the individual (or others) in imminent danger, it is worth investigating individuals’ claims to flourish or find meaning in virtue of their psychiatric disability.

Users/survivors’ accounts often reveal ‘meaning making’ that, while idiosyncratic, is nonetheless of the utmost personal significance to the patients themselves, their conceptions of their lives, and even, perhaps, the course of their condition.”

Mad Pride, Icarus Project, and many other user/survivor groups celebrate the unusual but valued modes of being that are possible with psychiatric disabilities. They openly reject the notion that psychiatric disabilities are sources of shame and alienation, as was described in the first chapter. Thousands of members worldwide share in this epistemic community and in these values, and users/survivors insist that their experiences with these disabilities do not fit the common tragic interpretation of their conditions. Outsiders’ evaluation of psychiatric disability will overlook these lived experiences and the subjective importance that these modes of being could have. The duty of recognition requires that, before paternalistically intervening, we listen to their first-person reports, critically

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215 See Freeman & Garety. There is no longer a firm distinction between neurosis and psychosis.
216 Strikingly, a recent survey found that 95% of Americans believe that mentally ill people are violent. In actuality, it is rare for symptoms to result in violence toward others. People with schizophrenia are frequently targeted with this stereotype: 60% of Americans believe that they are violent, but of those who have been convicted of interpersonal violence, only 0.5% of men and 0.05% of women were diagnosed with this condition (Cherry).
217 Angermeyer & Dietrich 170-171; Cherry 794
218 Radden, “Recognition Rights” n.pg
analyze our own presumptions, and engage in respectful discourse with those who have the relevant experiences.

DEMANDS FOR RECOGNITION IN DIFFERENT SOCIAL JUSTICE MOVEMENTS

In this section, I will illustrate how demands for recognition operate within a variety of social justice movements. These movements have different historical roots, and the people they represent have different lived experiences of injustice; yet, they share a concern about recognition. The details of recognition are not the same for all of the movements or for all of the groups and persons within the movements. Over time, demands for recognition take a different tone, based on how the surrounding society’s laws, policies, and institutional mechanisms have addressed or overlooked the various injustices that occur at different levels of social and political life. They can also take a different tone as the groups’ identities change over time, depending on how the identities have received uptake or been reconstituted by the surrounding society. Moreover, there is always a danger in writing about recognition for any given “group,” such as ethnic minorities or persons with disabilities, since these groups are heterogeneous, and glossing over their differences runs the risk of reifying impoverished and essentialized identities, thus perpetuating misrecognition. With these caveats in mind, I will provide brief analyses of recognition politics within different movements so as to contradistinguish them from user/survivor activism, which faces unique barriers to achieving recognition.
Among Cultural, Ethnic, and Racial Minorities

Paradigmatically, recognition politics champions the rights of cultural minorities to achieve respect, visibility, and accommodation within a dominant culture. The harsh effects of cultural imperialism on minorities’ traditions, practices, education, child rearing, and language typify misrecognition. Will Kymlicka states: “Groups claiming minority rights insist that at least certain forms of public recognition and support for their language, practices and identities are not only consistent with basic liberal-democratic principles, including the importance of individual autonomy, but may indeed be required by them.”

There will be concerns whenever outsiders to the minority culture try to determine what support is sufficient to discharge duties of recognition. If cultural minorities receive accommodation based on outsiders’ judgment of what is fair and appropriate, then any seeming advances could ultimately set back the movement in the long run.

The positive project of recognition politics includes establishing safe spaces in which minorities can flourish according to their own conception of flourishing. Cultural, ethnic, and

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219 Grouping cultural, ethnic, and racial minorities together is potentially problematic, since they are each distinct. I discuss all three in this subsection because their fights for recognition are broadly similar. Some groups experience misrecognition across multiple dimensions of culture, ethnicity, and race. For discussions of recognition politics across these dimensions, see Yasmeen Abu-Laban’s analysis of misrecognition among Muslim Canadians post-9/11 (esp. 127) and Courtney Jung’s historical sketch of political struggles for Mexico’s indigenous populations (esp. 21-22). Additionally, there are potential dangers in trying to establish cultural recognition for any social group, since members in a group could have multiple divisions in their cultural identity. See, for example, Durukan Kuzu’s analysis of recent fights for recognition among Kurds in Turkey. The details of any given group will make all the difference for whether struggles for recognition succeed, and a seeming group might need to splinter for specific forms of misrecognition to be addressed adequately.

220 Kymlicka 21. He prefers the term ‘accommodation rights’ to ‘recognition rights’ because the former “helps emphasize that we are not just discussing a symbolic desire for recognition, but also substantive changes in the way institutions operate, so as to better meet the needs of a particular group (51, n.3). The way ‘recognition rights’ is used in this dissertation does not suggest that recognition is merely symbolic; as will be evident in this analysis, problems of misrecognition and material inequities are interrelated, and concrete changes are necessary to address both.
racial minorities have historically been pressured to assimilate into the dominant culture with minimal to no opportunities to continue their own identities and traditions. Demands for recognition are, among other things, fights against assimilation. For some minorities, these struggles have been successful in establishing “various self-government powers, which enable them to live and work in their own educational, economic, and political institutions, operating in their own language.”

When minorities’ fight for recognition succeeds, the political and moral expectations of minorities are no longer for them to bend themselves to the dominant culture.

Many minorities are not given the opportunity to govern themselves in separate institutions or separate communities, and some minorities would prefer to be able to pursue their distinctive mode of being with acceptance and respect within the institutions of the surrounding society. For them, recognition will involve making existing spaces safer, more welcome, more open to their distinctiveness without stigmatizing them. For instance, when racialized profiling associates non-white races with criminality, a foreseeable result is that non-white persons are subjected to more scrutiny and fear reactions than white persons. Whether formally adopted by law enforcement or informally accepted by civilians, racialized profiling puts non-white persons at increased risk for unjustified force and increased burdens when traveling (whether from work to home or across seas). Endorsement of racialized profiling by government agencies can perpetuate explicit or implicit racist associations within the general public. Fraser points out that practices like racialized profiling are “instances of misrecognition [that] cannot be redressed by a politics of redistribution alone. On the contrary, the only way to overcome the injustice is to replace institutionalised cultural patterns that subordinate people with patterns that establish

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221 Ibid. 51
them as peers.” Regardless of what other political or economic rights these minorities have, social justice will not be achieved as long as misrecognition persists through policies like racialized criminal profiling.

In addition to these positive projects, recognition politics critiques flawed reforms intended to address injustices, such as difference-blind rules. Difference-blind rules (e.g., color-blind admissions and educational improvements) purportedly help institutions and individuals to focus on factors like merit instead of group affiliation (such as race). Instead of discriminating among groups of people, difference-blind policies are supposed to ensure that “likes are treated alike,” thereby achieving fundamental justice for all groups. Rather than serving justice, though, difference-blind policies tend to backfire by overlooking differences that are relevant for determining what needs, interests, and perspectives are at stake. These policies are built on the myth that existing institutions are neutral when, as Kymlicka highlights, institutions are “implicitly or explicitly tilted towards the interests and identities of the majority group.”

Moreover, difference-blind policies fail by framing justice as merely a matter of civil, political, and welfare rights. Kymlicka argues that the fight for minority rights has to go beyond these rights by “emphasizing the importance of certain interests which have typically been ignored by liberal theories of justice—e.g., interests in recognition, identity, language, and cultural membership.” If these other interests are not accommodated, then moral harms and injustices will persist for these groups in virtue of their minority status, regardless of what other

222 Fraser, “Why Overcoming Prejudice Is Not Enough” 24
223 Kymlicka 33
224 Ibid.
rights are respected. Studies over the years show that color-blind approaches “diminish the accuracy of individuals’ social judgments, increase decision-making errors, and magnify racial bias […] [and] may also reduce sensitivity to potentially meaningful racial differences.”

Difference-blind policies can therefore have pernicious effects on individual attitudes and reasoning toward minority groups, which can impede recognitive stances interpersonally.

For cultural, ethnic, and racial minorities, the politics of recognition makes distinctive contributions to achieving justice. Some minorities have been able to attain a level of self-government so as to pursue their own language and traditions with fewer hindrances. For many other minorities, the struggle for justice includes fighting for recognition as equal members of society, so they are not viewed as deviant or criminal. Others. When recognition interests go unacknowledged, difference-blind rules can be instituted with the mistaken justification that they serve justice. Demands for recognition made by these minorities can be similar to those of other marginalized groups, though the particular forms of misrecognition that they experience in public and private spheres could present their own challenges.

**In the Disability Rights Movement**

Within the disability rights movement (DRM) over the decades, the call for recognition has multiple parts. Misrecognition is apparent when individuals with disabilities do not have access to equal participation opportunities, and misrecognition occurs when their valued identities are invisible or unintelligible to others. From the beginning of the movement, disability
activists have rallied around the call “Nothing about us without us!”

This slogan expresses the plea for greater inclusion of persons with disabilities in all levels of decision-making related to their interests. There is a justice claim and an epistemic claim embedded in this plea: a) their exclusion is unwarranted and unjust, and b) persons without disabilities have an insuperable epistemic barrier when it comes to understanding the lived experience of disability. When they are denied a voice and position of power in decision-making, the marginalized status of disabled individuals is further perpetuated. Sarah Goering contends that “voices of disabled people demand recognition, and fair recognition cannot take the form of hearing but immediately discounting their position.”

If disabled individuals’ claims are continually solicited but then dismissed, considered briefly but subverted, incorporated initially but ultimately lost, then their status as equals has not been sufficiently recognized.

Individuals with disabilities have been historically marked as defective and degenerate, and many continue to face infantilization and paternalism in many spheres of life. Their recognition politics includes a demand to not be reduced to body parts or treated as dysfunctional agents. As Rosemarie Garland-Thomson puts it: “Because disability is understood to disqualify us from access to the benefits and status of the properly human, it is a place that we do not go willingly or welcome into a life, perhaps especially in a contemporary time and place.”

Disability is framed as the ultimate disqualifying condition—what disqualifies someone from

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226 See historical overview and discussion in Charlton.
227 Goering, “‘You Say You’re Happy, but…’” 133
228 Garland-Thomson, “The Case for Conserving Disability” 340
flourishing, independence, and a meaningful life. As such, disability is viewed as something to be avoided and pitied, which results in misrecognition in many spheres of daily living.

Garland-Thomson explains that “what counts as disability legally ranges across a broad spectrum of physical, motor, mental, sensory, behavioral, medical, and appearance conditions that restrict function and full participation and are understood as stigmatized and exclusionary ways of being.” According to the standard biomedical model, disability is understood in terms of limitations that are internal to the individual (i.e., the limitations are attributed to the impairment instead of primarily environmental factors). These limitations might affect the extent to which someone can engage in “normal” citizenship or participation. As long as disability is framed this way, individuals with disabilities will regularly confront assumptions that they should be fixed – even assumptions that they would want to be fixed and ought to be grateful for attempts at fixing them, that they should welcome charity. These assumptions can make it difficult for persons with disabilities to be invited as equal partners, since their perspective is so often interpreted by others through a lens of pathology and dysfunction.

Some of those within the DRM advocate for the conditions necessary for “normal” living and “normal” citizenship as a matter of public recognition. In a report to the 1969 President’s Committee on Mental Retardation, Bengt Nirje famously argues for the normalization principle, according to which “you act right when making available to all persons with intellectual or other impairments or disabilities pattern of life and conditions of every day [sic] living which are as close as possible to or indeed the same as the regular circumstances and ways of life of their

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229 Ibid. 341
communities.” Nirje’s work was highly influential in the history of disability rights advocacy. Along these lines, Honneth asserts that subjugated groups historically achieved recognition by gaining mutual esteem based on visible accomplishments that have social or economic value. If individuals with disabilities can receive esteem for social or economic accomplishments that are comparable to those of other people in their society, then they will be closer to achieving recognition as equal members of society. When this esteem is part of recognition politics, it follows that individuals with disabilities should have the necessary political, economic, and social rights to make these accomplishments possible. This version of recognition politics within the DRM fits a politics of universalism, and it does not challenge the normative expectations contained within “normal” living or citizenship.

Other activists within this movement instead emphasize that disability can present valuable modes of being that should not be restricted, suggesting that they have distinctive identities that ought to be supported. Taking their first-person perspectives seriously, Sara Goering argues, involves trusting their reports of well-being: “positive evaluations of their lives from disabled people warrant attention, and the alternatives values may be recognized as reasonable.” As was mentioned in the prior chapter, the DRM challenges able-bodied persons to acknowledge that impairments do not necessarily preclude a good life; moreover, it is possible to flourish in virtue of so-called disability, not despite it. Garland-Thomson makes this point: “these lived experiences provide individuals and human communities with multiple opportunities for expression, creativity, resourcefulness, relationships, and flourishing. The persistent forms of

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230 Nirje, qtd. in Parmenter 277; also see Nirje, web §4.
231 Honneth; van den Brink & Owen 17
232 Goering, “You Say You’re Happy, but…” 131
human biodiversity we consider disabilities witness sturdiness more than fragility, interdependence more than isolation.”

As with many disability rights activists, Garland-Thomson wants so-called disability to be viewed as a natural form of human biodiversity that ought to be conserved.

Jackie Leach Scully holds that only individuals with disabilities can “reframe emergent identities more positively, redescribing disabled subjects and their lives in their own terms rather than anyone else’s […] The epistemic advantage of the group prises open and makes explicit the gap between the behavior prescribed by the majority society and the lived reality of the minority group.”

On this view of recognition within the DRM, it requires an openness to these claims and sources of value, trusting first-person lived experiences over imposed assumptions that denigrate disabled modes of being.

Many persons with disabilities form their own supportive communities that welcome reclaimed language (such as the word ‘crip’), inclusive forms of communication and mobility, and innovative artwork and performance that speak to their lived experiences. Disability culture is associated with disability pride (or Crip Pride), for which there are parades and efforts to build solidarity and raise awareness.

Co-founder of the Institute of Disability Culture, Steven Brown, describes disability culture as follows: “People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our

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233 Garland-Thomson, “Human Biodiversity Conservation” 13
234 Scully, Disability Bioethics 147-148
236 Brown, Steven, “Disability Culture and the ADA” n.pg.
experience of disability. Most importantly, we are proud of ourselves as people with disabilities.” For those who share in this culture, part of public recognition would include having access, accommodation, and opportunity to celebrate their culture together without stigma or medical judgment. Societal efforts to support cultural pluralism would cover disability culture as well.

In the private sphere, recognition would include establishing the conditions necessary for persons with disabilities to feel and express their pride and letting them speak for themselves on the meaning of that pride. For example, it would be a form of misrecognition if stories of disability pride were (intentionally or not) misconstrued to be stories of “triumph in the face of tragedy” – since disabilities can be experienced as sources of strength and bonding, not as tragedies. Athletic events that include someone with a physical or cognitive disability often have this unfortunate feature, where a simplified and repackaged version of the individual’s story is used by commentators to serve as inspiration for others to “push through adversity.” As a case in point, the Special Olympics are controversial among disability rights activists. Opponents argue that the event gives a demeaning faux-opportunity to express disability pride; instead, the Special Olympics end up reinforcing negative stereotypes, the Otherness of disability, and demeaning language. The Board of Directors for the Special Olympics has also been notoriously exclusionary for persons with disabilities. This event fails to support disability pride, and it contributes to misrecognition by using persons with disabilities as tragic-yet-inspiring examples.

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237 Brown, Steven, *Movie Stars and Sensuous Scars* 80-81
238 Storey
Furthermore, interpersonal recognition would mean the elimination of pitying attitudes toward disability. Pity taints relationships that otherwise could be built on mutual respect and appreciation for each other’s differences. A pitying attitude presumes that the other person is suffering, but this attitude is misplaced and patronizing when that person does not consider herself to be suffering. Someone with a disability might experience lack of equal opportunity and discrimination, but pitying attitudes are often directed at her as if the impairment is an inevitable cause of those misfortunes. Joseph Stramondo argues that pity toward individuals with disabilities has another problematic dimension as well: “pity does not ever exist among equals.”

Stramondo locates pity in interactions between oppressors and the oppressed. To express pity is to put oneself above the other; the attitude is that between a “have” and a “have-not,” between someone who has social power and someone who lacks that power. And because pitying attitudes are generally socially sanctioned as kind-hearted, they do not receive the same scrutiny or self-reflection as some other problematic attitudes that feed into marginalization and stereotypes. As Stramondo argues: “First, pity does nothing to change or even acknowledge socially created harm. Second, the existence of pity rests on the very power differential that created the social harm in the first place.”

When pity creeps into interpersonal relationships, the pitied person is expected to fall in line with the suffering narrative; that is, the pitied person is expected to confirm that she is suffering. If she claims not to be suffering, then pity can even increase, since the assumption is that she is in denial about her experiences. Pity, then, carries with it presumptive distrust of non-conforming narratives. In all of these ways, pity fuels

239 Stramondo 125
240 Ibid.
241 Ibid. 131
misrecognition in relationships since having valued identities respected and achieving participatory parity will prove difficult when these attitudes are prevalent.

In the Deaf Gain Movement

Deaf Gain has philosophical ties to the disability rights movement, though Deaf persons generally view themselves as a linguistic and cultural minority instead of a disability group. Deaf Gain attacks institutionalized ableist (or audist) biases that undervalue distinctive modes of being associated with Deafness. The rise of Deaf activism occurred partly in response to attempts in the twentieth century to eliminate sign language in schools and elsewhere. The privileging of oral language and discounting of Deaf culture, called oralism, fit “in a particular approach to biological difference—one that is intent on fixing, rehabilitating, and minimizing the distance between the normal and what is seen as pathological.” Deaf Gain challenges the push for cochlear implants as a form of oralism.

When deafness is framed as a tragic deficit, deaf persons’ refusal to be “normalized” with devices and speech therapy can be seen as irrational and perhaps even irresponsible (e.g., when parents make this decision for their children). Gerald E. Loeb, who co-developed cochlear implants, stated in 1993 that his device would lead to the “‘extinction of the alternative culture of

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242 I use ‘deaf’ to refer to persons who cannot hear and ‘Deaf’ to refer to deaf persons who identify as part of a cultural and linguistic minority. See Editor’s Note in Deaf Gain: Raising the Stakes or Human Diversity xiii; Harmon 126; Obasi 457. Some activists want to replace the word ‘Deaf’ with ‘signing people’ or ‘people of eye’ or ‘ASL-PERSON’ to emphasize their linguistic status instead of the biomedical status (Harmon 128).

243 ‘Audism’ covers the system of privilege granted to hearing persons in virtue of their hearing, and it is associated with degrading and stigmatizing life without hearing (Harmon 125).

244 Bauman & Murray xvi

245 Ibid.
the Deaf, probably within the decade.” Groups like Deaf Gain assert deaf persons’ right to protect their linguistic community against assimilation and attempts at extinction. Deaf activists argue that they deserve the recognition of other cultural minorities, which could involve having their own schools, safe environments for communicating through sign language, supports to raise children without pressures to “normalize” them, and respect for their own folklore and artistic contributions, even their own music. Recognition for Deaf culture would also include supporting and respecting prospective parents’ desire to use assisted reproductive technology to have deaf children. Misrecognition occurs when clinicians, genetic counselors, or others negatively judge these parents for wanting to bring a genetically “defective” child into existence, particularly because this judgment relies on the assumption that the child would be better off without d/Deafness.

Some Deaf activists argue that framing Deafness in terms of disability is its own form of misrecognition, since it undermines the efforts of Deaf persons to present themselves as a linguistic and cultural community. They fervently reject any attempt to use disability discourse or disability rights to assist Deaf persons with their own recognition politics:

The fact that the disability movement is complicit in the construction of Deaf people as disabled also carries weight in maintaining this label in the legal, political, and social arenas of the wider society. It adds a valuable contribution to hegemonic depictions of Deaf people as disabled. It cements the allegiance of the hearing disabled and nondisabled majority that excludes the Deaf cultural discourse.

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246 Qtd in ibid. xvii
247 Laurent Clerc National Deaf Education Center n.pg.
248 Obasi 459
249 Ibid. 457
For Deaf persons who view themselves as a distinctive identity that ought to be recognized, they assert their right to self-definition that is not based on disability. They define themselves not in relation to a hearing majority, not in terms of loss, and not in terms of a medical category. Their inability to hear does not define them individually or collectively, and “the myopia of [a disability-oriented] perspective prevents us from looking beyond audiology to see the fuller picture of visual and linguistic plenitude identified from within Deaf culture theorizing.”250 From this standpoint, Deaf persons instead embrace a linguistic and cultural identity that has distinctive value. The notion behind Deaf Gain is that they have gained Deafness, a valuable mode of being. Just as other linguistic minorities would not be considered disabled, many Deaf persons believe that they similarly should not be viewed as disabled. Although there are benefits to allying with persons with disabilities for the sake of recognition, these Deaf activists would rather ally themselves with other cultural minorities.251

Interpersonal recognition of Deafness would include respectful methods for gaining deaf persons’ attention and welcoming them to communicate in their preferred modalities.252 Teresa Blankmeyer Burke recounts psychological advantages to embracing Deafness and not conforming to audist expectations, such as choosing not to wear hearing aids or attempting speech-reading. In her experience, she encounters less annoyance and impatience when she openly identifies herself as Deaf and shares communication with a note pad. She suggests that “judiciously choosing when to experience life as a Deaf person might be a way to reduce dismissiveness and increase opportunities for respectful, civil interaction in one’s daily life

250 Ibid. 458
251 Ibid. 458-459
252 Laurent Clerc National Deaf Education Center n.pg.
encounters."\textsuperscript{253} She furthermore suggests that Deafness offers a unique type of intimacy, since signing and interpreting require significant trust and vulnerability in the sustained gaze of visual communication.\textsuperscript{254} Interpersonal recognition for Deaf persons would include a sustained gaze that does not objectify or sexualize\textsuperscript{255} the Deaf person; the gaze would instead invite open communication and connection on the Deaf person’s own terms, as an equal participant in the dialogue.

\textit{In the Neurodiversity Movement}

The neurodiversity movement shares features with the disability rights movement and Deaf Gain. Activists argue that they have been unfairly pathologized, which leads to many forms of misrecognition in policies, research programs, clinical encounters, and everyday living. The term ‘neurodiversity’ is attributed to sociologist and autist\textsuperscript{256} Judy Singer, who wrote in 1999 that “‘the key difference of the ‘Autistic Spectrum’ lies in its call for and anticipation of a politics of Neurological Diversity, or what I want to call ‘Neurodiversity.’” The ‘Neurologically Different’ represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability.”\textsuperscript{257} ‘Neurodiversity’ is meant to cover those diagnosed with neurological or neurodevelopmental disorders, including attention deficit-hyperactivity disorder, bipolar disorder, developmental dyspraxia, dyslexia, epilepsy, and

\textsuperscript{253} Blankmeyer Burke 8
\textsuperscript{254} Ibid. 12
\textsuperscript{255} Except, of course, when a sexualized stare is welcomed and appropriate in the context.
\textsuperscript{256} Neurodiverse individuals generally prefer person-first language, such as ‘autistic person’ or ‘autist,’ instead of ‘person with autism.’
\textsuperscript{257} Qtd. in Armstrong 7
Tourette’s syndrome, though activism from autistic persons is the most prominent.\textsuperscript{258} This movement argues that 1) neurodiversity is a natural variation of human existence; 2) neurodiverse modes of being are inseparable from these persons’ identity; and 3) these modes of being are worth valuing and celebrating.\textsuperscript{259} As put by activist-scholar Thomas Armstrong: “we need to admit that there is no standard brain, just as there is no standard flower, or standard cultural or racial group, and that, in fact, \textit{diversity among brains is just as wonderfully enriching as biodiversity and the diversity among cultures and races}.”\textsuperscript{260}

Some neurodiverse individuals strive for recognition of a distinctive culture\textsuperscript{261} as a source of belonging and pride, taking inspiration from Deaf Gain’s claims of Deaf culture. Recognition must include removing the stigma associated with neurodiverse conditions and seeing these individuals as political agents who can form their own culture. Persons diagnosed with neurological or neurodevelopmental disorders are often viewed as having a form of difference that is categorically separate from ethnic, racial, or cultural minorities, however. There are immediate obstacles to receiving recognition for neurodiversity:

Autistic people, when they are the focus of public policy, are rarely framed as citizens who possess rights, hopes or aspirations, much less ideas about politics. They are characteristically dependent upon the good will or benevolence of others, whether they are sympathetic policy makers who have been ‘touched’ by autism or the loving parents and caring friends who perform much of the ‘emotional labour’ that autism requires.\textsuperscript{262}

\textsuperscript{258} Jaarsma and Welin 21; Armstrong.
\textsuperscript{259} Jaarsma and Welin 21; Armstrong; Kapp et al.; Brown, Lydia
\textsuperscript{260} Armstrong 3, italics from text
\textsuperscript{261} Claiming \textit{cultural} recognition has its critics within the movement, since doing so runs the risk of “reifying culture and, particularly in the broader world of autism research, implying that culture is something Others (Brazilians, Indians, Italians, ‘Aspies’) ‘have’ and a ‘default’ white Anglo-Saxon neurotypical person does not” (Cascio 209). ‘Aspie’ is a person-first way of referring to an individual with Asperger’s.
\textsuperscript{262} Orsini 2012, 808
Neurodiverse persons contend that the heart of their identity is at stake; neurodiversity is not merely something they *have* or *live with* – it is something that underlies their sense of self and how they think about their lives and set ends.

Some within the neurodiversity movement claim that they deserve special protection and entitlements, arguing, for example, that “autistic culture is unfairly disadvantaged in the cultural marketplace. Political recognition and support can rectify this disadvantage. The viability of the autistic culture may be undermined by economic and political decisions made by the majority of neurotypicals.”263 If an environment accommodates neurodiversity as a cultural identity, then they might not experience disability at all, they argue. Their traits could be viewed as neutral or even positive, as something that should be protected as a form of cultural difference.264 Their recognition politics emphasizes the importance of building social, economic, and clinical reforms based on the input of neurodiverse individuals themselves, since “the situated knowledge of people living with autism [or other neurodiverse conditions] legitimizes their political involvement.”265 They insist that neurological and neurodevelopmental disorders266 should not exclude someone from participatory parity.

The neurodiversity movement shares with the DRM its rejection of biomedical modeling: “A political identity among autistic self-advocates, and disabled people more generally, positively relates to a proud identity and opposition to treatment toward a cure.”267

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263 Jaarsma and Welin 2011, 26
264 Ibid. 28; Orsini 2012, 807
265 Orsini 2012, 815
266 Some within this movement differentiate based on the type of disorder/condition, as described in the below discussion.
267 Kapp et al. 60
clinical research protocols and medical therapies aimed at eliminating unusual but harmless behaviors (e.g., repetitive body movements), and they oppose genetic counseling and reproductive technologies that try to prevent the birth of neurodiverse children.\textsuperscript{268} They emphasize that they can have a meaningful and flourishing existence that is not separable from their neurodiversity. Attempts to “fix” their conditions are especially problematic when these ameliorative efforts do not take into account first-person perspectives and what neurodiverse individuals value. Temple Grandin makes the point, shared by many others in the movement, that curative efforts are not welcome: “If I could snap my fingers and be nonautistic, I would not. Autism is part of what I am.”\textsuperscript{269}

While some self-advocates oppose all medical interventions, others say the acceptability of certain therapies depend on what the self-identified needs of the individual are. For example, some activists differentiate between high-functioning autists (HFA) and low-functioning autists (LFA), claiming that the former group alone has recognition claims based in cultural identity. This distinction is controversial within the movement: “While some neurodiversity scholars and autistics find the popular differentiation between HFA and LFA offensive, parents and carers of children whose autism is characterised as LFA fear that their very real differences may be obscured by neurodiversity rhetoric.”\textsuperscript{270} Part of the difficulty is discerning which behaviors, abilities, and levels of intelligence should be viewed as part of a cultural identity and which are not. If Asperger’s syndrome is the only condition covered by the neurodiversity movement, this “suggests that those with the skills to become persuasive activists as well as to contribute to the

\begin{footnotes}
\item[268] Ibid.
\item[269] Qtd. In Jaarsma & Welin 21
\item[270] Mackenzie & Watts 34
\end{footnotes}
wider society in ways in which are valued may succeed in having their differences accepted.”

This view of recognition politics will be overly narrow for many individuals who identify as neurodiverse but who do not have Asperger’s. These activists want to expand what counts as successful and valuable modes of being. They strive to be contributing members of their own communities and not to have their achievements based on what is expected in the neurotypical community.

Misrecognition occurs when neurodiverse persons are excluded from decisions about how to classify their conditions, which research programs to fund, and which medical interventions could be valuable. For example, the neurodiversity movement opposes Autism Speaks for being an organization that strives to “fix” autism, arguing that it perpetuates ableist ideals and excludes many voices of the people they claim to support—autistic persons. Some activists have tried to eliminate conditions like Asperger’s Disorder from the Diagnostic and Statistical Manual of Mental Disorders, arguing that the DSM pathologizes what should be viewed as a condition worth celebrating and embracing. The vast funds, institutional resources, and human labor spent every year on trying to cure certain neurological or neurodevelopmental disorders could arguably be spent in a more just manner if they were geared toward restructuring society to accommodate this form of difference instead. This redistribution

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271 Ibid.
273 Jaarsma & Welin 24-25
274 Presumably, not all neurological or neurodevelopmental disorders would fall under the neurodiversity movement. For example, vegetative states and dementia are generally excluded from these discussions of valuable human difference.
should go hand-in-hand with inviting leadership from neurodiverse individuals, who should be viewed as political and social equals instead of patients to be managed.

Public recognition will not be sufficient, since “even where legal and social welfare mechanisms intended to foster participatory equality are in place, stigmatisation and ignorance may compromise quality of life for such people and their families and carers.” Interpersonal recognition for neurodiverse individuals would involve using person-first language (e.g., ‘autistic persons,’ ‘autists,’ ‘Aspies’), since doing so shows respect for their neurodiversity as a central aspect of their identity. Similarly, denigrating language (e.g., ‘retarded’) would be replaced with self-defined and empowering terms (e.g., ‘neurodiverse’). Interpersonal recognition could also include providing safe spaces for whatever behaviors (e.g., self-stimulation or stimming) they find comforting, as well as not negatively judging these behaviors when they are not harmful to anyone. In these ways, someone can demonstrate respect for a neurodiverse person’s self-defined identity and values.

DEMANDS FOR RECOGNITION AMONG USERS/SURVIVORS

Since the literature for the user/survivor movement is not as extensive as the literature for other movements, their demands for recognition are not as well-articulated or well-known. To clarify what their recognition politics would involve, it is useful to compare and contrast their recognition needs with those of other social justice movements. Following this analysis, I turn to

275 Mackenzie & Watts 33
277 Ibid.; Orsini 818
the first-person reports of users/survivors. By examining their narratives, I draw out what their demands for recognition are, given their own views on mental diversity.

**Contrast and Comparison with Other Social Justice Movements**

Similar to some racial, ethnic, and cultural minorities, psychiatric users/survivors argue that they should have safe spaces to resist assimilationist pressures. For those who believe that they cannot comfortably pursue their mode of being in a welcoming environment of like-minded individuals, having a separate community might be more desirable than trying to revolutionize mainstream society. Since the beginning stages of the user/survivor movement, their activism included calls for peer-run support groups, as these were seen as more therapeutic than medical institutions or clinics. These separate communities also provide more freedom for their behaviors and creative endeavors without the threats of stigma. Additionally, users/survivors challenge stereotypes that associate their identities with dangerousness and criminality. Pervasive misperceptions that all persons with psychiatric disabilities are inclined toward violence or all people inclined toward violence are psychiatrically disabled can have devastating effects. Persons with psychiatric disabilities can meet hostility when they try to live openly and pursue the modes of being they find worthwhile.

But unlike racial, ethnic, and cultural minorities, users/survivors cannot as easily claim a group identity that is based on a common history, shared language, a set of traditions and worldviews, or facing oppressive structures and attitudes from birth. Users/survivors also

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278 Chamberlain
confront regular doubts about their epistemic standing, and these doubts may or may not be justified. Historically, racial and ethnic minorities faced similar doubts due to supremacists’ use of Darwinist theories to try to show that non-white, non-Anglo Saxon persons were intellectually and cognitively inferior. In trying to achieve participatory parity, racial and ethnic minorities had to fight against these pseudoscientific and mistaken views to show that they should be welcomed as equal partners and contributors. Today, epistemic doubts about ethnic and racial minorities are (generally) not as widespread or pronounced as they used to be. For many users/survivors, these doubts continue to be part of everyday existence.

As discussed in other chapters, the disability rights movement and user/survivor movement have many parallels, and this includes the nature of their recognition politics. With their slogan “Nothing about us without us,” the DRM argues against unwarranted exclusion of persons with disabilities in policy discussions and other decisions that pertain to their way of living. Able-bodied persons cannot easily imagine what their values and interests would be if they experienced disability; similarly, individuals who have never experienced psychiatric disability cannot easily imagine what it would be like to value auditory hallucinations or manic states. Users/survivors claim patient expertise and the primacy of patient narrative, suggesting that their epistemic privilege into their condition would be good reason to establish participatory parity.

Like those within the DRM, users/survivors insist that their disability does not necessarily disqualify them from flourishing, independence, or meaningfulness. Many persons with disabilities, physical and psychiatric, claim that they would not take a “magic pill” to cure
their condition, since their condition speaks to who they are. The recognition politics of both groups includes challenging dominant interpretations of disability, since claims about disability being a valuable form of difference are unintelligible according to the biomedical model. For their form of diversity to receive credence and accommodation, DRM activists and users/survivors reject the pathology lens that only sees them in the sick role. Members of both groups challenge the values and assumptions behind normalization, and they instead want to raise awareness of the novels ways of living and thinking that can be available to those who have a disabled mode of being. The DRM and user/survivor movement aim to form their own supportive communities with reclaimed language (e.g., ‘crip’ and ‘mad’), inclusive accommodations, and their own artistic outlets. Pity as a form of interpersonal misrecognition is pervasive for both groups.

In their struggles to achieve recognition, the DRM and user/survivor movement will encounter similar opposition to their value claims. According to one strand of opposition, the subjective reports of persons with disabilities are unreliable because of the problem of adaptive preferences. Martha Nussbaum articulated the problem: “habit, fear, low expectations, and unjust background conditions deform people’s choices and even their wishes for their own lives.” Based on this line of reasoning, any person with a long-standing disability (physical or psychiatric) will be a poor judge of what is a worthwhile existence, since “better” forms of living are outside their experience and thus outside their understanding and appreciation. These opponents undermine the recognition claims made by the DRM and users/survivors. This

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279 Goering, “‘You Say You’re Happy, but…”” 129
280 Nussbaum 114
opposition assumes, though, that 1) there are better (not merely different) forms of living, and 2) the preferences of persons with disabilities are being lowered (not merely adjusted). Both of these assumptions can be challenged by individuals within the DRM and users/survivor movement, but to be successful, their epistemic standing needs to be recognized. They need to be respected as knowers if they are to show the ableist errors in quality of life measurements and if they are to demonstrate the worth of their preferences. This respect will be more difficult to achieve for individuals diagnosed with psychiatric disabilities. Although both groups experience infantilization and paternalism, persons with psychiatric disabilities can have every piece of testimony subjected to scrutiny depending on others’ interpretation of their diagnosis.

Deaf Gain strives for recognition of Deafness as a linguistic and cultural minority, and many Deaf persons argue against any medical amelioration. Many Deaf persons believe that recognition of their distinctive identity requires refusal of cochlear implants, and physicians who encourage the devices are arguably perpetuating misrecognition. While users/survivors do not claim to be a linguistic minority, and it is not common for them to claim cultural minority status, they reject certain medical interventions. For example, users/survivors overwhelmingly reject medical interventions that are believed to erase their identity, like electroconvulsive therapy.

Deaf persons speak of gaining Deafness, as Deafness is viewed as a valuable mode of being and source of pride. In a similar vein, Mad Pride celebrates psychiatric disability and tries to reclaim a positive and distinctive identity. Users/survivors suggest the notion of generative madness, reframing psychiatric disability as a locus of meaning and creativity. Persons with congenital deafness will face paternalistic assumptions that their Deaf identity is based on adaptive

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281 Goering, “‘You Say You’re Happy, but…’” 131-133
preferences (from never having experienced hearing). In this way, Deaf persons and users/survivors will similarly struggle to be respected as knowers and to have their first-person perspective taken seriously. But as with the other groups mentioned above, Deaf Gain does not have the same obstacles to recognition as users/survivors, since D/deafness does not generally lead others to doubt their epistemic standing.

Like those within the neurodiversity movement, users/survivors emphasize the value of their modes of being and oppose therapies or treatments aimed at eliminating behaviors they view as unusual but harmless. They exalt their conditions as sources of pride, and they assert their first-person expertise. The recognition politics of both groups will be inevitably complex, given the significant variation in conditions covered by neurodiversity and mental diversity. Dividing neurodiverse persons according to their functional status (e.g., high-functioning and low-functioning autists) is controversial and arguably undermines the recognition politics of the movement. Psychiatric users/survivors have not attempted such a division, though there are separate subgroups according to diagnosis or symptom (e.g., for those who hear voices, experience paranoia, and have episodes of mania). Both movements grapple with how to achieve recognition for persons who vary greatly in their cognitive capacities.

For individuals within both movements, stigma, stereotypes, and denigrating language (e.g., ‘retarded’) lead to misrecognition in relationships. Because the creative expressions and thinking processes of individuals within both groups might fall outside the mainstream, they will continually experience alienation within the larger community. This alienation is partly the result of others doubting these individuals’ epistemic standing. The neurodiversity movement has its roots in online activism from autists with Asperger’s, and these people might not face the same
level of scrutiny as individuals considered low functioning. Nonetheless, individuals within both
groups have to fight assumptions that their diagnoses necessarily disqualify them from
meaningful participation or contributions. The struggles for recognition within neurodiversity
and the user/survivor movement are substantially similar. Neurodiversity has grown to include
conditions that may be considered psychiatric disabilities, including hyperactivity and mood
disorders. Neurodiversity specifically celebrates different wirings of the brain, and in this way
this movement diverges from user/survivor activism. Many users/survivors would reject this
etiological explanation for psychiatric disability, favoring instead a social or interactionist model
of their disability.

First-Person Reports from Psychiatric Users/Survivors

To get clearer on what recognition specifically means for individuals with psychiatric
disabilities, we should let their first-person perspectives guide further analysis. The impetus for
significant social and institutional changes can originate in growing first-person reports of
abuses, marginalization, and forced assimilation; especially for groups who otherwise have
limited power and standing, telling these narratives can be one of the only early outlets for
receiving validation of their experiences, which in turn can lead to the formation of a community
of choice. When these coalesced narratives serve as the backbone for a community and help
set their foundational commitments against those of the larger society, they can serve as

282 Armstrong 27-52, 95-114
283 Friedman distinguishes found communities from communities of choice. Whereas found communities are given to
us by birth and are often steeped in oppressive practices, communities of choice offer “contexts in which to relocate
and renegotiate the various constituents of our identities” (95).
counterstories. A counterstory is “a story that resists an oppressive identity and attempts to replace it with one that commands respect.”\textsuperscript{284} They challenge master narratives, which encompass socially shared understandings that provide social points of reference that can denigrate or misrepresent the identity and values of certain groups.\textsuperscript{285} They can shape social perceptions of certain groups without anyone intentionally or explicitly employing the master narrative as such. The problematic assumptions or denigrating aspects of certain master narratives might not be consciously accepted by any person who references them, which means that individuals voicing counterstories can perpetually struggle to receive recognition among those who have not experienced similar injustices. The narratives of users/survivors challenge the master narrative, and some of their narratives are also counterstories.

Members of a marginalized social group\textsuperscript{286} could struggle to have their narratives given credence for a number of reasons, such as a presumption that their first-person reports are unreliable. Alternatively, it might not be easily believed that the group in question has an oppressed identity to resist. Current and former psychiatric patients who try to gather around shared narratives can face both of these obstacles. For almost fifty years, this group has been steadily growing in momentum as they identify damaging master narratives that work against them in a wide array of contexts—clinical, legal, financial, political, and others. These master narratives have a common, problematic assumption, according to this group: Psychiatric conditions, especially psychoses and severe and persistent mental illness (SPMI), are thought to

\begin{flushleft}\\textsuperscript{284} Nelson 6 \\
\textsuperscript{285} Ibid. \\
\textsuperscript{286} How someone becomes a member of a social group is a tricky question, sociologically and philosophically. For one, there is the question of what constitutes a distinguishable social group. Also, there is the issue of whether a person must self-identify with that group; it is certainly the case that someone can be treated as a member of the social group, regardless of what he/she endorses or denies. These problems are outside the scope of this project.\end{flushleft}
doom patients to a totalizing illness identity that consists in chronic pain and debilitation, a lower quality of life (based on the elusive, ill-defined baseline of ‘mental health’), the ever-present threat of decompensation, and the frequent need for paternalistic psychiatric intervention. Additionally, the master narratives suggest that individuals with long psychiatric histories are always prone to lose touch with reality or become clouded in irrational, delusional thinking. Although some conditions can have these effects (lost sense of reality, irrational or delusional thinking), not all do. Master narratives are blunt by nature; they do not discriminate keenly amongst individuals within the social group. In the face of these master narratives, many individuals with psychiatric disabilities claim they “grow up with life-denying meanings and are hostage to toxic stories that adversely define and constrain their identity and self-image.”

In response, users/survivors suggest “the task is first to understand this and then to find ways of modifying (re-authoring) these myths-people-live-by to promote a more constructive, effective and adaptive context for living.”

In examining the narratives of users/survivors, we should analyze barriers to having those narratives respected as challenges to the master narratives; after all, presumably there would be no need for a long-standing social justice movement unless there were these barriers. First, the diagnosis of mental illness (especially SPMI) can compromise someone’s ability to construct a recognizable narrative or a narrative that is respected as reliable and meaningful. Some psychiatric conditions could have the effect of lost coherence or diminished communication skills with the result that others could have difficulty grasping their first-person reports.

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287 Roberts 435
288 Ibid.
Alternatively, individuals with psychiatric disabilities, especially those subjected to regular hospitalizations and involuntary psychotropic treatments, might have fewer opportunities to create and maintain their narrative or counterstory.\footnote{Baldwin 1023} Also, as detailed previously, diagnostic labels can result in general scrutiny towards their first-person reports and identity claims.

If the psychiatric condition has affected someone’s sense of linearity or temporality, then her narratives might have an unusual form. It is moreover frequently noted that there is an underlying belief that a person with SPMI lacks reason to such an extent that he is not even aware of his lack of reason. It has been on the basis of the perception that people with [SPMI] become totally absorbed into their illness and thus lose touch with reality, that both narrative and self have been negated, leaving behind nothing more than an ‘empty shell’ of a person. Not only has this perception been shown to be false, it also has the effect of further abandoning the person to the illness, dismissing rather than inviting narrative.\footnote{Roe & Davidson 90}

These factors together lead to a common inclination to dismiss the narratives of diagnosed individuals, which would make them the “narratively dispossessed” in the words of one scholar.\footnote{Baldwin 1023} Additionally, master narratives can be employed “as a means to understand, contain or manage the challenge posed by the narratively dispossessed.”\footnote{Ibid.} By crafting a social justice movement around unashamed and frank personal narratives about living with a psychiatric disability, activists strive to “challenge both the imposition of the master narratives of the particular diagnosis by what they say and the master narrative of [‘mentally healthy’] narrative...
by how they say it.”293 In other words, they have found common cause and unity in their efforts to refute the “dominant narrative of pathology, chronicity, and decline.”294

While some former patients join the user/survivor movement because of reported abuses within the mental health system, other patients report a subtler kind of harm that motivates their activism. They lament being treated as someone to be managed, as unreliable patients who need heavy-handed interventions to prevent degradation of their well-being and agency. Patricia Deegan, a long-time advocate, imagines what she would tell herself at the point when she first entered the mental health system:

You are at a critical juncture, a very important time. The professionals are telling you that you are a schizophrenic. Your family and friends are beginning to refer to you as ‘a schizophrenic.’ It is as if the whole world has put on a pair of warped glasses that blind them to the person you are and leaves them seeing you as an illness… Almost everything you do gets understood in reference to your illness. You used to feel sad sometimes but now you are said to be depressed. You used to disagree sometimes but now you are told you lack insight. You used to act independently but now you are told that your independence means you are uncooperative, noncompliant, and treatment resistant…But now that you have been labeled with mental illness the dignity of risk and the right to failure have been taken from you. No wonder you get angry. 295

She expresses here many common concerns, such as having her diagnosis subsuming all other aspects of her identity. Her emotional reactions, claims to epistemic authority, and willfulness were reduced, in her view, to pathological states that were the direct result of her mental illness. Similarly, former patient Beate Braun says: “If you are diagnosed with schizophrenia, they talk with you like you are not there. They talk about you but not with you, but you have to hear it.”296

293 Ibid. 1027
294 Kirkpatrick 61
295 Deegan 361
296 Qtd. on MindFreedom International, testimony from 2002
In an anthology filled with first-hand reports from people who have auditory hallucinations, there are numerous stories of how hearing voices can be startling and off-putting to those who have never had the experience. Contrary to common opinion, these patients and commenting activists argue that these voices do not necessarily jeopardize their health, flourishing potential, or agency. Frans de Graaf provides a representative anecdote:

My problem with the healthcare services started when I came into contact with a physician. That physician told me the standard healthcare point of view: my experience is psychosis. I need medication for the rest of my life and my voices should not be discussed, since otherwise the psychosis will return. This meant that the voices were not accepted and this leads to a conflict. The conflict develops about the way in which you want to approach your experiences and what the underlying causes are. This conflict takes up so much energy, that you would have to end the relationship […] As soon as the diagnosis of schizophrenia has been given, I am regarded as not able to speak for myself, I am measured according to an average norm and a medical doctor has to be consulted to approve what I have said.²⁹⁷

The loss of epistemic standing in the minds of others is a frequently reported harm. These activists are reporting on widespread issues in their view; they are not merely reporting on “bad eggs” in the mental health system who are out to harm patients.

These narratives suggest the shape that their recognition politics could take. Users/survivors view their psychiatric disability differently than the general public, and they often face resistance when trying to reframe or re-define the nature of their condition. In trying to achieve accommodation for their form of diversity and participatory parity, they face similar problems as many other groups, including so-called accommodations that do not fit with their self-identified interests.

²⁹⁷ Qtd. in Living with Voices 165
CONCLUSIONS

In the last chapter, I show how different models of psychiatric disability can alter the interpretation of the lived experiences of individuals with these conditions. If user/survivor activism is to achieve its aims, redistribution of goods and services is not sufficient; they additionally want to claim a distinctive and valuable identity and be welcomed as equal contributors in society. To unpack this aspect of their activism, I started this chapter with the philosophical framework for recognition politics. I emphasized the normative import of recognition in public and private spheres, tying it to restorative respect in cases of marginalization. Achieving recognition will not be a simple task for users/survivors, however, which motivates a deeper analysis into the meaning of recognition for this group. While some individuals will be incapable of demanding recognition due to severe psychiatric impairment, I contend that many individuals with psychiatric disabilities will have sufficient standing to make claims on behalf of mental diversity. To help clarify what recognition politics looks like within social justice movements, I gave an overview of demands for recognition coming from other marginalized groups. I then compared and contrasted users/survivors’ demands for recognition with those of the other movements, highlighting the distinctive features that recognition politics would need to take for users/survivors. Against this backdrop, I discussed the importance of narratives for forming a more precise account of recognition politics. Users/survivors’ first-person reports reveal what forms of misrecognition they believe they experience in many areas of life, including inside and outside clinical settings. From here, we have a better understanding of what their concerns are from their perspective.
The particular value of mental diversity still needs further development, however. The next chapter delves into this issue, and I argue that modes of being associated with psychiatric disabilities can have profound and intimate value for those who experience them. Specifically, I show how these modes of being can be cared about because they are meaningful, so there are *prima facie* obligations related to others’ responsiveness to them. I focus on the interpersonal recognition that can be achieved in one of the most intimate and vulnerable relationships that individuals with psychiatric disabilities have—the therapeutic relationship.
CHAPTER FOUR: FINDING MEANING IN PSYCHIATRICALLY DISABLED MODES OF BEING

This dissertation is fundamentally dissecting a particular claim made by certain individuals with psychiatric disability: They value their mental diversity, and they want their disabled modes of being to receive recognition as another form of human difference. Many patients with psychiatric disabilities will be glad of their diagnosis and seek treatment to be rid of their condition, but I am restricting my discussion to those individuals who value their psychiatric disabilities and want their form of difference respected and protected. In the previous chapters, I have made the case that a) the claim to flourish in virtue of mental illness could be comprehensible if ‘mental illness’ were reconceptualized using an interactionist disability framework, and b) there are compelling moral reasons, arising from duties of recognition, to take this type of claim seriously. In this chapter, I will investigate what constitutes a disabled mode of being, the ways in which it can be valued by someone, and when the valuing of a mode of being will have _prima facie_ claim on others’ respect and responsiveness.

Part of my aim in this chapter is to lay out how the mode of being must be valued for it to be eligible for demands for recognition. The capacities of the individual will be highly relevant, especially in cases of psychiatric disability. If it turns out that the psychiatric condition has distorted her thought processes and emotions so drastically as to make all of her relevant desires fleeting and unstable, then her claims will have a different kind of moral pull on us. Promoting the interests of someone in a severely decompensated and fragmented state will rely heavily on external judgments of what is in her best interests.\(^{298}\) In this scenario, the duty of beneficence

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\(^{298}\) When caring for someone with severely decompensated psychiatric disability, caregivers should still take into account what the individual currently finds pleasing and do their best to accommodate these desires. This is why I claimed that when someone merely desires her psychiatric mode of being, there is a _different kind_ of moral pull on
would outweigh any duty of recognition; the issue of respecting mental diversity will not be a compelling consideration in this case, since the individual’s condition has undermined her capacity to extract personal value in her style of living. There is significant room for philosophical disagreement on how a mode of being needs to be valued for it to lead to duties of recognition. I will argue that a mode of being that is cared about and meaningful will have profound personal value. If someone values her disabled mode of being in this way, then prima facie duties of recognition hold.

My analysis will further illuminate the overly narrow focus in bioethics on autonomy and well-being. These two distinct values are supposed to be fundamental to understanding the patients’ interests, and ethical tensions between the provider and patient are often framed by bioethicists as a conflict between concerns about autonomy on the one hand and concerns about well-being on the other. A patient’s autonomy could be relevant because the patient has decisional capacity (and is therefore entrusted to make her own decisions) or because the patient currently lacks capacity, but providers are trying to respect prior autonomous wishes or trying to restore capacity for future decisions. Standard medical care also emphasizes health and overall wellness, trying to secure such goods as stability, safety, and symptom reduction. Meaningfulness tends to be hedged out of these conversations; when discussing the patient’s relevant history, values, and preferences, what counts as meaningful to the patient does not tend to be a discussion topic. If it does come up in the clinical conversation as part of the patient's

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us. The issue in these cases is how to advocate for the individual’s best interests, which may or may not involve respecting the aspects of her condition that she finds pleasing. There could be alternative ways to satisfy her first-order desires, and pursuing these alternatives will not necessarily carry a moral cost. This is of course not to deny that individuals in these severely compromised states can nonetheless be harmed. See above note.
narrative, it can be easily reduced or reframed as part of the patient’s autonomy or well-being interests. Meaningfulness has some overlap with these values, and a decision could have all of these features—being meaningful, autonomous, and contributory toward well-being. There is vast philosophical literature on conceptions of autonomy and well-being, but meaningfulness as a value is distinctive. In discerning what is meaningful to patients with psychiatric disabilities and how this value should be traded off against others, there will be some unique challenges that I explore.

In the first section, I explain what a mode of being is, and I connect this notion with disability. Next, I consider what it means to value a mode of being. I build on the work of Agnieszka Jaworska and Cheshire Calhoun to argue that modes of being that are cared about because they are meaning have central importance to someone’s identity. The remaining parts of the chapter focus on psychiatrically disabled modes of being that are cared about because they are experienced as meaningful. Modes of being that are valued in this way are ripe for recognition, but there will be challenges for respecting mental diversity. I close with an analysis of prima facie obligations that mental health professionals have when they are caring for patients who claim to find meaning in cared-about modes of being that are associated with their psychiatric disability.

**MODES OF BEING**

I will define ‘mode of being’ as follows:
mode of being – a loosely correlated cluster of activities, lifestyle choices, freedoms, limitations, and lived (as opposed to idealized or non-actualized) priorities that largely contribute to someone’s everyday experiences and actions, which in turn shape that person’s sense of self and sense of belonging.

Importantly, a mode of being, as defined above, is not necessarily good or bad in any sense. Someone can build their end-setting, sense of self, and sense of belonging around a mode of being that is laudable or corrupt, empowering or demeaning, healthy or unhealthy, supportive of well-being or self-harming. A mode of being can be the result of intentional choices, as well as unintentional ones. It emerges over time; no single snapshot of someone’s life can reveal the details of her mode of being. A mode of being could be complex with some contradictions (as when someone’s enduring priorities never quite cohere with one another), but it could also be relatively simple.

The complexity of the mode of being will partly depend on the cognitive and affective complexity of the individual; someone with a profound intellectual disability could have a mode of being, though it could involve relatively simple preferences and choices and activities. One person could have more than one mode of being, depending on context and different roles. For example, someone could have one mode of being while spending time as a parent but a separate mode of being while in the office. Any one mode of being could be unified or fractured to different degrees, depending on a number of factors, including personality and the stability of life circumstances. For a mode of being to be identifiable as such, though, it cannot be completely fragmented; the activities, lifestyle choices, freedoms, limitations, and lived priorities have to be at least minimally connected to each other if they are to help coordinate the individual’s everyday life and sense of identity.
Of note, the above definition does not presume that a mode of being has to be chosen autonomously. As suggested above, this cluster of activities and traits can emerge over time, even without the intentional or voluntary input from the individual. Someone with diminished autonomous capacities, such as an individual with profound intellectual disability, could have a mode of being that reflects aspects of everyday life that were largely chosen by others. An adolescent could be thrust into religious rituals that become central to her mode of being; even if she feels unfree to choose otherwise, she could still have a mode of being that is characterized by a religious lifestyle that affects the priorities that guide her everyday planning and interactions with others.

Modes of being can be vulnerable to suppression, fragmentation, and alteration for a variety of reasons. For example, someone without independent mobility in a long-term care facility could significantly depend on caregivers for creating opportunities to make choices, pursue a particular lifestyle, or participate in various activities. Such an individual could end up with a highly diminished mode of being if those opportunities are rare. For individuals with cognitive and intellectual disabilities, they can be heavily reliant on caregivers when trying to craft their own mode of being. For individuals with chronic and severe pain, they might need daily opiate use and end up spending long amounts of time secluded from others at home, making it difficult to consistently pursue activities that otherwise would contribute to their sense of identity and community with others.

See analysis in Ells regarding the vulnerability of residents with disabilities in long-term care facilities, particularly in relation to making choices and having options.
A major life event can make it seem like someone has suddenly switched into a new mode of being, but its details will need to take shape through the individual’s lived experiences and choices in relation to the life event. For example, Dax Cowart experienced catastrophic burns and injuries after a gas fire, and his former athletic lifestyle and priorities were expected to change drastically after the fire. Cowart could not begin to guess what his new mode of being in his newly disabled state would be like, which led to his making inaccurate assumptions about how valuable a disabled mode of being could be in the months following the fire.301

Not all modes of being will be valued by the individual who lives it. As in Dax’s case, anyone could fall into a mode of being that she finds fearful or unwelcome. Disability activists and psychiatric users/survivors argue that modes of being that are not able-bodied or able-minded can have value to those who experience them. As such, they can come to value these modes of being, which is supposed to imply that there are prima facie obligations to respect this form of diversity and to set up the conditions necessary for those modes of being to be enjoyed or pursued.302 I will explore some of the different ways in which a mode of being can be valued in the next section.

301 Cowart & Burt. Cowart admits that he undervalued life with disability before he experienced it, and fear of a disabled mode of being was one of his central motivations for refusing treatment at the time and preferring death (excruciating, poorly controlled pain being the other central motivation). In bringing up this example, I am not denying Cowart’s moral right to refuse treatment as a capacitated patient.

302 These prima facie obligations have positive and negative dimensions to them, since there will be calls for non-interference as well as the provision of certain protections and accommodations, as elaborated in the last section of this chapter.
There are many ways in which someone could value something, and capacities to value can be more or less cognitively complex and demanding. I accept Agnieszka Jaworska’s description of what it means to value something – namely, the individual believes what she wants is worth wanting; achieving what she wants is connected to her sense of self-worth; and she believes it has importance even if it does not currently give her pleasure or satisfaction.\textsuperscript{303} She conceives of valuing as having a relatively “stable set of purposes and preferences.”\textsuperscript{304} Importantly, valuing is not equivalent to high-order reflection; that is, something can have personal value even if it has not been endorsed in a process of critical deliberation. This means that valuing is possible for individuals who fit in a broad range of cognitive abilities; valuing is not limited to persons who are intellectually engaged at the highest levels with their choices.

Jaworska argues that someone could be capable of valuing even if unable to “devise and carry out the means and plans” for following her values, due to (e.g.) perpetual confusion or memory lapses.\textsuperscript{305} Moreover, she argues that valuing is possible even if it “becomes uncoupled from the person’s grasp of the narrative of her whole life.”\textsuperscript{306} In other words, someone could retain the capacity to value even when not completely alert or oriented or cognizant of details of her life as a whole. Jaworska makes this point by examining cases of patients with dementia, who are still able to value certain things even if they no longer know their precise age, date, or location.\textsuperscript{307} Her analysis of dementia has many parallels with the analysis I offer regarding

\textsuperscript{303} Jaworska, “Respecting the Margins of Agency” 116.
\textsuperscript{304} Ibid. 128
\textsuperscript{305} Ibid. 127-129
\textsuperscript{306} Ibid. 117
\textsuperscript{307} See “Respecting” 117, case of Mrs. D and others.
psychiatric disability. Although some forms of psychiatric disability are so profound that they diminish the capacity to value, the presumption should be that most individuals with psychiatric disabilities will be able to reach the cognitive threshold needed for some form of valuing.

Valuing is contrasted with merely desiring. Mere desires are fungible and fleeting, so their being obstructed does not pose significant harms to the agent as an agent.308 Jaworska describes mere desires as distinctive in that “a person could contemplate being free of a mere desire with a sense of relief.”309 It is constitutive of mere desires that they do not occupy a place of importance to the agent, that the person could have those desires go unsatisfied without feeling much in the way of regret or indignation. If someone merely desires a mode of being, that mode of being cannot have a central role in how that individual views herself. Given what a mode of being is, this appears to be incoherent. Someone could find certain aspects of a mode of being to be subjectively desirable, but a mode of being is not fungible. A mode of being cannot be sustained through mere desires. If someone is driven by mere desires only, then her life will be pulled in too many directions for a mode of being to form.

A mode of being can be cared about. Caring is a way in which something can be valued.310 Jaworska provides the following account of caring:

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308 This is not to deny that repeatedly obstructing someone’s mere desires can have a cumulative effect that end up being significant for individuals who have diminished moral interests. Any singular instance of an unmet mere desire would not be particularly harmful, though, and these mere desires do not form the basis of forms of difference that ought to be protected in the name of pluralism and recognition.
309 Jaworska, “Respecting the Margins of Agency,” 114. According to Jaworska, persons can “distinguish between desires and attitudes that merely occur within him and those that are truly his own” (“Caring” 538).
310 Whether caring is a type of valuing on Jaworska’s account is open to interpretation. I offer a plausible reading, since caring would not fall into the category of merely desiring. Further, Jaworska’s analysis of valuing among individuals with dementia has striking parallels to her analysis of caring among these individuals. Valuing is not a highly intellectualized notion on her account, so the emotional capacities involved in caring could constitute a form of valuing.
[I]t is best understood as a structured compound of various less complex emotions, emotional predispositions, and also desires, unfolding reliably over time in response to relevant circumstances. Typical components of caring include: joy and satisfaction when the object of one’s care is flourishing and frustration over its misfortunes; anger at agents who heedlessly cause such misfortunes […]\(^{311}\)

Caring is a special kind of investment on the part of an agent. It is an investment that incorporates a number of attitudes and attunements—emotional in nature—that are responsive to the fate of the object of caring. This kind of emotional investment directs an agent’s actions, intentions, affective responses, and end-setting. As a structured compound, carings “forge a vast network of rational and referential connections that support the agent’s identity over time”.\(^{312}\) In other words, in cases of caring, someone’s emotional episodes and desires will reference one another and build off of one another. When an agent cares about something, she “structures her plans and intentions to promote it.”\(^{313}\) As a result, carings support the individual’s sense of self and her own agential perspective—which is what makes them authoritative in “speaking for” who the agent is.\(^{314}\) From the individual’s point of view, then, the objects of caring have enormous importance for the continuity of her agency, and the “grasp of importance is necessary for a caring attitude to inspire the agent to organize (unify) his actions and intentions around that which matters.”\(^{315}\)

\(^{311}\) Jaworska, “Caring and Internality” 560

\(^{312}\) Ibid. 561

\(^{313}\) Ibid. 563, n. 97. Jaworska comments that the agent’s emotional attunement must not contradict what the agent believes is factually true, or else those emotions will seem external (“baffling”). I gather from her examples and discussion in this footnote that the agent’s beliefs might not be actually true, but if the agent believes them to be true, then the corresponding emotions will not strike the agent as baffling. The subjectivity of the agent will matter more than the objective facts, since carings can be misplaced or in error, as Jaworska suggests (see also pg. 564, n. 99).

\(^{314}\) Jaworska champions a “more permissive account of internality”, which “is this: any attitude, reflexive or not, has the right kind of authority to speak for the agent, so long as it is part of its function to support the psychological continuities and connections that constitute the agent’s identity and cohesion over time” (ibid. 552).

\(^{315}\) Ibid. 564
I would emphasize at this point that someone can care about an array of things, including more than one mode of being. Especially when someone is capable of having a multitude of interests and emotional investments, it should be expected for that individual to care about numerous things. Although having all of these carings could pull someone in multiple directions at once, they all contribute to the whole of who the person is. Carings orient someone’s interaction with the world—what she prioritizes, pays attention to, craves. Having diverse carings makes someone complex, not disunified. Being stuck in a conflict between carings does not negate the ways in which those carings are unifying for the individual’s sense of self. For example, someone who cares about her professional mode of being and parental mode of being might feel conflict at times, not able to do everything that she cares about due to various constraints. Rather than experiencing this conflict as disunifying (as if she is not a whole agent), she could experience it as tragic precisely because these carings are both integral aspects of her complex sense of self.

Jaworska suggests that the cognitive and affective elements of caring are present in children and many patients with Alzheimer’s. Degeneration or underdevelopment of cognitive capacities will not always preclude the possibility of caring. Caring involves capacities that are complex but not overly demanding. Jaworska argues that caring provides the most basic structure of human agency, and she distinguishes it from the highly intellectualized capacities for second-order volition or full-blown autonomy.316 These more sophisticated capacities, following from the works of Harry Frankfurt and Ronald Dworkin and others, are more complex forms of valuing. They involve subjecting one’s stable preferences to critical evaluation and then

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316 See “Caring and Internality” 567 and “Respecting the Margins” 130.
endorsing them after this high-level reflection. Jaworska’s point is that these sophisticated capacities are not necessary for an agent to be capable of valuing; the emotional attunements involved in caring are sufficient for an agent to have a differentiated sense of self with agential projects she can consider her own. Given that an agent can maintain her carings while experiencing memory losses or failures in means-end reasoning, even significant psychiatric disabilities will not always eliminate the possibility of this form of valuing. The objects of caring could change as a result of psychiatric episodes, but especially given that the objects of caring will never be rigidly fixed for anyone, these changes are not necessarily problematic. For now, the important point is that many individuals with psychiatric disabilities can retain the ability to care about their modes of being, barring the degradation of these relatively basic capacities.

**CARING ABOUT A MODE OF BEING BECAUSE IT IS MEANINGFUL**

There are innumerable reasons why an agent could care about something. The reasons might not be well-articulated, even in the agent’s own mind. Again, caring does not require higher order endorsement, so the reasons behind the carings might not have received deep or even conscious reflection. Jaworska gives the example of someone who is emotionally drawn into a war, devastated by the news that it has broken out, despite previously believing that the war is of no importance to her.\textsuperscript{317} Carings could also run contrary to someone’s considered judgments or second-order desires, as when a woman in an abusive marriage cares about her

\textsuperscript{317} “Caring and Internality” 538-539
spouse, despite not wanting to care. The reasons behind carings reveal further details of the individual’s motivations, attitudes, and other values and desires.

The reasons why an agent cares about a mode of being are important for understanding the place of importance it ultimately has for her. We already know that a mode of being is important for how someone carries out her everyday living; we know that carings provide agential perspective by structuring the individual’s emotional predispositions and desires. But depending on the reasons for caring about the mode of being, it could be held more or less dear. A cared-about mode of being will affect the person’s sense of self and agency, but the agent may or may not embrace this fact. The agent might be eager to abandon the cared-about mode of being, or the agent might fight to protect it from disruption. The reasons make a difference to the agent’s moral interests and thus a difference for how others should respond to the cared-about mode of being. Meaningfulness, I suggest, gives a cared-about mode of being value that could transcend all other values for a person, which means it would incur the most cost to lose. I will unpack what it means for a mode of being to be meaningful, what is distinctive about meaningfulness, and then what would make a mode of being both cared about and meaningful, as well as the normative implications of someone having such a mode of being.

When we think what could make a mode of being meaningful, there are several closely related and competing concepts that could be relevant. For instance, we might think a mode of being is meaningful when it is praiseworthy. A mode of being that centers around charity and bringing people together for the communal good, for example, might be paradigmatic as

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318 Ibid. 538
meaningful. If we judge this mode of being as meaningful, we are assessing the ends which are served—charity and communal togetherness—as ones that are full of meaning. There are a couple of problems with equating a meaningful mode of being with a praiseworthy one, though. The evaluation of meaningfulness loses its distinctive significance; to determine whether a life is meaningful, we would use the same criteria as we would use for determining whether it is deserving of (moral, cultural, or other) praise.\(^{319}\) Further, even if a mode of being is laudable, it can still feel empty from the standpoint of the person who has adopted it. What we find meaningful in is far more individualized. What has meaning in the sense of being praiseworthy does not always have meaning for any given agent. She might feel stunted, inhibited, deeply ambivalent, or otherwise detached from her life as a result of the mode of being not holding meaning for her personally—regardless of how others view her life.\(^{320}\)

Cheshire Calhoun suggests that “[m]eaningful living involves expending your life’s time on ends that in your best judgment you have reason to value,” given the finitude of your time and energies.\(^{321}\) She points out that when we decide to invest ourselves in something, “the cost is not just to you, but also of you […] whatever you spend your time on uses a bit of you up.”\(^{322}\) Calhoun’s point is that, due to our finitude, any investment results in an expenditure of what little

\(^{319}\) Cheshire Calhoun makes this point: “one might have thought that the value of having a concept of meaningfulness is that it picks out something that is not identical with significant (or whatever other evaluative conception is driving the analysis of meaningfulness)” (1). She offers several critiques of agent-independent accounts that exclude a subjective dimension to meaningfulness.

\(^{320}\) Calhoun also argues that equating ‘meaningful’ and ‘praiseworthy’ leads to the conclusion that “among equally agent-independently valuable pursuits, none could be more meaningful specifically for you” (5). She suggests that there are personal factors that could make a difference for which pursuit is meaningful, however.

\(^{321}\) Ibid. 12. Calhoun’s analysis of ‘meaningful’ focuses on ends and agential projects. Colloquially, we speak of objects and events being meaningful – e.g., a childhood blanket or family reunion. But these are not part of Calhoun’s analysis, as she is focused on meaningful living. Similarly, I am focused on what makes modes of being meaningful.

\(^{322}\) Ibid. 10
we have and are; this expenditure means we do not have that time or energy for other things. Any project that becomes the focus of end-setting will have different spending levels: primary spending on those activities that are our ends, as well as entailed spending on those means that are necessary for achieving our ends.\textsuperscript{323} Choices can emerge as meaningful in expected and unexpected ways, sometimes taking up more of our time and energies than we foresaw. Depending on what we find meaning in—e.g., a mode of being versus a singular hobby disconnected from other interests—we can become increasingly invested, which will mean escalating our value trade-offs and personal sacrifices. We can find ourselves in a spending loop as our investments demand more of us, entailing more and bridging our interests so that we pick up new related projects. All of this is to underscore the fact that what we find meaningful will be significant. Who we are will set the course for what we find meaning in, and what is meaningful to us will shape who we are in turn. Meaningful choices will affect what gives us pride and regret, contentment and dissatisfaction, and overall a sense of purpose.

Calhoun argues that we form a \textit{normative outlook} based on our evaluation of which ends we should pursue and what is worth the personal cost to us. The normative outlook is largely subjective, since it depends on how a particular agent makes choices in virtue of her values and value trade-offs. The reasons behind a meaningful pursuit might be reasons that anyone could evaluate and accept (what Calhoun calls “reasons-for-anyone”), which we can use to justify our ends to ourselves and to others.\textsuperscript{324} These reasons are not necessarily objectively right, but they have intelligibility and currency in public discourse. Calhoun explains that “they figure

\textsuperscript{323} Ibid. 11. She also discusses filler spending and norm-required spending, but they are not crucial for my points here.

\textsuperscript{324} Ibid. 12
prominently in interpersonal evaluative practices that involve reason-giving and reason-
receiving: giving advice, making recommendations, exhorting, criticising, correcting,
condemning, justifying, and defending.”

Reasons-for-anyone provide a metric for determining whether a pursuit is meaningful, and if we cannot offer any of these public reasons, then we will struggle to defend our choice to others. These reasons could have appeal to the wider public, but they might instead work within a smaller deliberative sphere (e.g., for only those within a certain culture or religion).

Calhoun suggests that our normative outlook also consists in reasons-for-me and reasons-
for-the-initiated. Reasons-for-me reflect who the individual is particularly, and they are not necessarily shared by others. They could incorporate “what the activity symbolises for you, its connection with your past, the fact that you made a commitments, its suiting your personality and natural talents, that others would be disappointed in you if you didn’t adopt this end, that you enjoy or love it, and so on.” These reasons might be intelligible to others, but they function to make a difference to the individual as far as which choices are made over others, which sacrifices are acceptable and which are not. If the reasons-for-me were completely idiosyncratic and if no reasons-for-anyone could be offered, then the choice would not be defensible to others. Since neither of these reason types track what is objectively right, someone could find meaning in something that is idiosyncratic and indefensible to others but nonetheless not wrong. In other words, the person could still have reasons that make sense from her particular normative outlook, even if other actual people or some idealized agent would not make that choice.

325 Ibid.
326 Ibid. 13
327 Ibid.
Reasons-for-the-initiated will only appeal to individuals who have experience with the specific pursuit.\textsuperscript{328} The pursuit could have various costs or even harms associated with it that will not strike others as worth the sacrifice, or the benefits of the pursuit might be so unusual that others are not inclined to appreciate them without experiencing them first. If something is meaningful primarily because of reasons-for-the-initiated, then the sympathetic group will be relatively narrow. If the pursuit is uncommon or stigmatized, then the initiated group could be extremely small, making it difficult to find others who believe it is worth the expenditures in energy and time.

What combination of reasons-for-anyone, reasons-for-me, and reasons-for-the-initiated factor into someone’s normative outlook will be highly individualized, which means that what someone finds meaningful will be subjective, though constrained by what the agent truly finds valuable. Calhoun argues that we do not find meaning in what merely evokes positive attitudes. If mere pleasure or desire were sufficient to confer meaning, then choices meant to bring meaning to someone’s life could not be criticized—even according to the agent’s own judgment.\textsuperscript{329} But when we strive toward meaningfulness, we are often tortured, preoccupied, and anxious about these decisions. The search for meaning can be a life’s endeavor that defines who a person is, tying together her values and strengthening her relational attachments. To say that the search for meaning is simply a search for positive attitudes belittles the experience and the weight of these decisions. Moreover, as Calhoun elaborates: “An attitudinal subjectivist eliminates from the conception of meaningfulness the very things that would enable the person who claims to have a meaningful life to explain the intelligibility, and thus meaningfulness, of

\begin{footnotesize}
\textsuperscript{328} Ibid.
\textsuperscript{329} Ibid. 16
\end{footnotesize}
his choices—his reasons." On Calhoun’s account, what we find meaningful reflects what we value and what sacrifices we believe are worth are time, energy, and efforts. These choices will be up for criticism by others and by ourselves.

**Meaningfulness, Well-Being, and Autonomy: Differences and Implications**

A meaningful mode of being will not necessarily support the individual’s well-being. Someone could become invested in a mode of being because she views it as worth valuing and worth the personal sacrifices, even if it makes her worse off in some other sense. Objective list theories of well-being suggest that there are fundamental dimensions of well-being, regardless what someone otherwise values. When there are set criteria for what constitutes a flourishing life, what someone finds meaningful could fall outside of those criteria. Considerations of well-being may constrain what someone chooses to invest in, since most of us value flourishing as well as meaningfulness, but that need not be the case with all pursuits. For instance, suppose someone chose to live as a pipe-smoking recluse with minimal contact with the outside world, even for medical care. This way of living could provide her with meaning because of how it fits with her personality and sense of nostalgia and romanticism; this same mode of being has significant drawbacks when it comes to fundamental components of well-being, such as health and social bonding.

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330 Ibid.
331 There are several objective list views, but I reference Powers and Faden’s neo-Aristotelian conception, since it captures important points of consensus with these views.
Similarly, hedonistic accounts of well-being leave room for someone to make choices that are meaningful but not consistent with well-being. For example, someone’s religious convictions could lead her to embrace suffering and pain in her mode of being because of their purported redemptive value (which requires still experiencing them as suffering and pain), making those experiences meaningful though contrary to well-being on a hedonistic conception. Desire or preference satisfaction accounts of well-being could be constructed to include meaningfulness. Whenever someone finds meaning in a pursuit, the satisfaction theorist could argue that a preference has been fulfilled, so well-being is always served whenever meaning is found. But even if meaningful decisions always contribute to well-being on desire or preference satisfaction accounts of well-being, those things that contribute to well-being on these accounts will not always be meaningful.

What promotes well-being will not always be meaningful. Someone’s life could be a flourishing one from an objective standpoint, but it could still be disconnected from those pursuits that the person believes are worth her time and energies. Objective list views provide elements of well-being that are supposed to be valuable to any human being, though they could make room for personal value trade-offs within a certain range. Even in allowing trade-offs, though, this conception does not waver in what constitutes well-being, and a minimum threshold would need to be met or at least accessible along all of the dimensions for the life to be a good one in terms of well-being.\textsuperscript{332} Any given dimension of well-being, such as health as traditionally defined or social attachment with other persons,\textsuperscript{333} might hold little to no meaning for an

\textsuperscript{332} Powers & Faden 15; Nussbaum
\textsuperscript{333} These are two of the six dimensions described by Powers & Faden 17-28, the others being personal security, reasoning, respect, and self-determination.
individual to attain, depending on her personality and how she weighs the personal costs of those elements of well-being in comparison to other pursuits.

The important point is that someone could agree that these are dimensions of well-being without finding meaning in them. If she constrained herself to those pursuits that supported well-being exclusively, she could still believe that her life does not reflect all of the idiosyncrasies and personalized components of her normative outlook. Moreover, it will not make a relevant difference how she attains well-being on an objective list view; pursuits that contribute equally to well-being will be weighed the same in terms of their contribution to a flourishing life, even if some of those pursuits would reflect her identity or personality more than others.\textsuperscript{334}

If we consider other conceptions of well-being, we run into similar problems. For hedonistic accounts, what maximizes short- and long-term pleasure over net pain will not always match what we believe we have reason to value and spend our time on. Pleasures of similar magnitude and duration would be weighted the same, even if it makes a difference to us which of these pleasures are pursued. With desire/preference satisfaction accounts, our preferences and desires can reflect different aspects of our psychology. We might prefer something because of its social benefits in our particular culture, even if we think these cultural engagements are an unfortunate necessity in this community. We would otherwise choose not to comply with cultural expectations, but given their pervasiveness and consequences for social and occupational mobility, we prefer to shape our lives around them. This mode of being would still be lacking in meaning based on how meaning is conceptualized above, even if it was necessary for attaining well-being in that context. This process is how people can come to believe that they are trapped

\textsuperscript{334}This is similar to Calhoun’s concern about conflating laudable and meaningful projects.
in meaninglessness, despite having a life that would count as a flourishing one based on markers for well-being.

Although most meaningful choices will be autonomous, someone could conceivably find meaning in possibilities that have been severely restricted due to autonomy-undermining pressures. There are numerous philosophical conceptions of autonomy, but the reigning conception in bioethics comes from Tom Beauchamp and James Childress. They argue that autonomy fundamentally involves making deliberative decisions that are voluntary, intentional, and with understanding. Meaningfulness requires that we pursue what we, in our best judgment, believe we should value and expend our time on, which could still be possible for someone whose pursuits have been less than voluntary, intentional, or with understanding. For example, if a woman goes through with an arranged marriage in a culture that teaches it is shameful to refuse, there could be doubts that this mode of being was arrived at in a robustly autonomous manner. She might also experience coercive pressures inside or outside the marriage to maintain a mode of being that fits expectations of a wife. Despite these worries, a woman in this situation could find great meaning in this mode of being. Given what she had available to her, embracing this role in a way that reflects her interests and values could make the marriage meaningful. She could consistently acknowledge that the marriage was not the result of deliberative free choice but still worth valuing and worth her time.

\footnote{Beauchamp \& Childress 101}

\footnote{In her narrative about her arranged marriage, Debie Thomas says: “To arrange a life is also to love and protect it, to put every bit of scaffolding in place to prevent collapse and chaos. It’s an ongoing tension, messier than the words ‘arranged marriage’ would suggest. This is how we manage our lives. We try to do it well.” Her narrative highlights the complexity and the tension of an arranged marriage, where the relationship might not include a right of refusal but still be worth valuing. Her experience could be framed as a meaningful one, even if the decision was not robustly autonomous.}
Further, an autonomously chosen mode of being is not necessarily meaningful. Even if an option has been researched, weighed against alternatives, and been chosen freely, it could be elected for reasons that have nothing to do with its meaningfulness. An autonomous choice can result from considerations of convenience or even indifference; after having weighed the options, a person could decide that none of them matter at all for her, leading her to make an arbitrary (though autonomous) choice. This is a way in which we can “fall into” modes of being over time that are not personally valued. Although autonomous choices can confer meaning, whether they do will depend on the extent to which an agent believes the pursuit is what she should “use herself up on,” as Calhoun says, given the preciousness of her finite time and energies.

The above analysis demonstrates that meaningfulness is conceptually distinct from well-being and autonomy. In helping someone pursue what is of value, morally relevant interests should not be reduced to those related to autonomy and well-being alone. Meaningfulness emerges as an area for moral concern that should not be neglected, especially when trying to convince someone to make personal sacrifices for the sake of other goods, such as a notion of health that might not mean much to the individual.

*Moral Interests at Stake: Pleroma and Identity*

I argued that different reasons could underlie why someone cares about a particular mode of being; for example, she could care about something because of its fit with cultural

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337 With this evocative phrase, Calhoun is presumably not saying that we should use up all of ourselves on any given thing we find meaningful. Human agents generally find many things meaningful. The point is that, in finding something to be meaningful, we have judged that it is worth an investment of our time and energy, which is significant given our limited capacities and time on earth.
traditions, its contribution to well-being, or because of some other value. On Jaworska’s account, caring involves being agentially invested in a project in a way that structures affective attunements and end-setting. Meaningfulness, on Calhoun’s account, depends on what the individual believes she has most reason to value and use her finite time and energy on. Even though carings provide an agential perspective, those carings might not bring her much meaning. Her carings might exact a great personal cost for her, and those sacrifices might not be worth it from her normative outlook. A meaningful caring, then, is an emotional investment that the individual believes is worth the investment. When a mode of being is cared about because it is meaningful, I will call it a pleroma, from the ancient Greek term for that which fills or is fulfilling. Pleroma was historically used to describe those things which filled ships that were brimming and full to abundance. When someone’s living is characterized by a mode of being that is meaningful and cared about, pleroma is an apt term. And just as a ship could be largely defined by what fills it, an individual’s life can largely be defined by cared-about modes of being that are meaningful to her.

To elaborate on the import that pleroma has for an agent, consider how we form our sense of self. David DeGrazia describes how we reflect on and value the continuity of personal identity over time in terms of self-narrative:

Each of us has a mental autobiography, an extremely detailed story of what we have experienced and done and perhaps less detailed account of what we intend, or at least hope, to experience and do. This autobiography is not a mere listing of personal events and intentions. The story is richly colored by a sense of one’s own beliefs, desires, values, and character – which affect which events are remembered and how they are

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338 The term pleroma is used in a variety of ways by Herodotus, Aristotle, Aristophanes, and theological writers. My use of it, as that which fills something to abundance, fits with some of its earliest usage in ancient texts. See discussion by Marvin Vincent and John Dillon. I am grateful to Jamie Watson for helping me find this term.
remembered, make sense of and even help determine plans for the future, and shape the overall self-conception of an enduring protagonist.\textsuperscript{339}

This self-told story reflects how we see ourselves within the context of our personal history and our changing social environment, though DeGrazia and others argue that these narratives will have constraints if they are to be legitimate and self-constituting.\textsuperscript{340} But even if some narratives, such as those that involve substantial falsehoods about reality,\textsuperscript{341} do not count as legitimate self-narratives, there could conceivably be multiple possible stories that could capture someone’s identity. These different stories would fit within the predetermined constraints (and therefore be legitimate) but narrow in on different features of someone’s life, bringing some events or aspects of her personality into focus while fading out others. Two people could theoretically have the same objective facts true about them (e.g., their education, family make up, successes and failures) and yet diverge in their self-told story, depending on how each perceives those facts.

According to DeGrazia, we should privilege the first-person perspective on the content and shape of someone’s self-narrative, since the identity question (“Who am I?”) that matters to us in our daily living\textsuperscript{342} “seeks a highly personal answer that, among other things, filters through

\textsuperscript{339} DeGrazia, \textit{Human Identity and Bioethics} 80.
\textsuperscript{340} DeGrazia strongly privileges the subjective interpretation of self, though he suggests that self-told stories need to be reasonably plausible (ibid. 84-86). Marya Schechtman says that legitimate self-narratives have an articulation constraint (“the narrator should be able to explain why he does what he does, believe what he believes, and feels what he feels” (\textit{The Constitution of Selves} 114)) and reality constraint on facts and interpretations (“living the life of a person requires living in the same world as other persons” (ibid. 119)). Hilde Lindemann Nelson elaborates on the credibility constraint of legitimate self-narratives, which includes strong explanatory force (“constituting stories are those that don’t just take the evidence into account—they’re the ones that fit the evidence best” (93)), correlation to action (strong correlation to past and future action (95)), and heft (“If a story is important to no one from either the first-person or the third-person perspective, it isn’t even a candidate for inclusion in the set of stories that make up a personal identity” (96)).
\textsuperscript{341} Schechtman, \textit{Constitution of Selves}, 119-125; Nelson 88-100.
\textsuperscript{342} The relevant identity question concerns one of characterization—who I am as a psychological subject. This question is contrasted with the reidentification question, which concerns numerical identity, a metaphysical inquiry that rarely pops up in our daily living. See Schechtman, \textit{Constitution of Selves}, 68-69.
objective facts about oneself, deeming only some of them salient.”³⁴³ For the narrative to maintain its intelligibility and coherence, it needs to be held together in a way that allows the narrative to adapt to changes over time. For the narrative to be a story that can be told and owned by the person herself (and not only imposed by others), the elements of the narrative need to reflect her most significant investments and commitments. The narrative is formed through dynamic and active processes based on how the person exercises her agency and reflects on who she is and what she should value.³⁴⁴

What could perform the unifying work of a legitimate self-narrative? If there is more than one legitimate self-narrative possible, does it make a difference which narrative is told and embraced, implicitly or explicitly, by the person whose story it is? In response to the first question, there is no one unification system for someone’s narrative identity; how the story hangs together, brings in novel additions to her identity, and pushes out increasingly irrelevant aspects will vary with the individual. Marya Schechtman suggests that a self-narrative contains “a dynamic set of organizing principles, a basic orientation through which, with or without conscious awareness, an individual understands himself and his world,” and the story is a “continually developing interpretation of the course of one’s trajectory through the world.”³⁴⁵ How a person makes sense of her life will be based on what she takes stock in, what she prioritizes in her self-conception. Her narrative’s orientation could be geared towards her pursuit of well-being, but it could also (for example) centrally revolve around exercises of autonomy and

³⁴³ DeGrazia, *Human Identity and Bioethics* 84.
³⁴⁴ This is akin to what Schechtman says: “the psychological forces constituting identity are dynamic and active—things a person *does*—rather than static and passive features she *has*” (*Constitution of Selves*, 117).
³⁴⁵ Ibid. 116
control, what she cares about, or what she finds meaningful. In response to the second question, I suggest that it will matter to the person which of the possible legitimate narratives is chosen because a) of how stable or unsteady the organizing principles are and b) to what extent the organizing principles make the story cohere in a way that can be owned by the individual. These two considerations go hand-in-hand; if a narrative is unified in a manner that can be owned by her, then it is more likely to be stable.

When something is cared about and brings meaning to the individual, it will hold a central place to her interests; this project or pursuit will not be neatly fungible, so its loss would be morally costly. Especially when a mode of being is at stake (not a singular hobby or activity), it will function like a nucleus for defining who she is as an agent; it will bind together that which is the most authentic and dear to her, what she judges to be most worth her finite energies and worth structuring her life around. Other carings, other things the person finds meaningful, and other ends will revolve in closer or more peripheral circles around this nucleus, depending on how they relate to this core aspect of her identity. If this core, this *pleroma*, were threatened or abandoned, then at stake there are a) what connects the person’s agency over time, and b) what the person believes she should expend her time on. When a mode of being has this significance, then its centrality to her sense of self and sense of belonging will mean that it will not be easily overridden by other considerations. *Even if* the *pleroma* threatens other goods, such as health goods, it will have moral weight.
**pleroma associated with psychiatric disabilities**

A *pleroma* is associated with a psychiatric disability when behaviors and dispositions behind the lifestyle choices result from the disability; the agent would not have the *pleroma* she does were it not for the disability. For example, someone with auditory hallucinations could be invested in a *pleroma* that centers on engagement with the internal voices. Without the psychiatric disability that underlies the hallucinations, the individual would presumably not have this particular mode of being. On first glance, a voice hearer’s normative outlook might seem to be founded on idiosyncratic reasons-for-me; that is, the meaningfulness derived from this mode of being might seem to be based in peculiarities of this individual’s personality and desires. If the voice hearer claims a *pleroma* without being able to articulate defensible reasons to others based on what is commonly valued, then the voice hearer might experience stigma and isolation while struggling to have the *pleroma* respected as such.

The psychiatric user/survivor movement reveals that in many of these cases, the deep reasons-for-me are actually tapping into an explanatory story for reasons-for-the-initiated. For others who have experienced the *pleroma* associated with the psychiatric disability, the reasons provided by an individual could be more defensible and even more intelligible. The experiential knowledge of the individual is shown to be less idiosyncratic. The INTERVOICE network of voice hearers from around the world is just one community where these individuals gain epistemic standing in relation to their experience. Voice hearing is just one example of many that could be given across the vast, heterogeneous range of psychiatric disabilities. The testimony from these user/survivor groups about their disabled *pleroma* indicates that outsiders to the experience are not always in the best position to judge how idiosyncratic a normative outlook is.
This also means that duties of recognition for these groups do not necessarily presume radical subjectivism; they need not demand accommodation for difference “just because this person chooses it.”

For individuals with psychiatric disabilities who say that their associated modes of being constitute *pleroma* for them, they might not want to risk “losing themselves” through medical interventions that could affect their everyday functioning and attitudes. In the context of psychiatric intervention, if a patient reveals a psychiatrically disabled *pleroma*, it could come under intense scrutiny as part of the preemptive paternalism that these patients often experience. The patient’s valued mode of being could run contrary to health goals or at least not prioritize health goods. Even if a patient’s well-being is interpreted beyond mere *medical* well-being, the physician or therapist could believe that the disabled *pleroma* is detrimental based on certain objective considerations (objective because of the need for standardized judgments across patients).

If a patient with a psychiatric history has built a lifestyle that a health care professional views as risky, dysfunctional, isolating, or delusion-oriented, for instance, then there will be concerns about the patient continuing that mode of being. Mental health professionals routinely investigate their patients’ choices and habits to make sure they are not endangering themselves or others, and there could be interventions (such as involuntary or coerced hospitalization or treatment) if the danger is considered to be imminent. When interpreting what counts as

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346 I am grateful to Madison Powers for helping me flesh out this point.
347 Although any given health care professional could adopt a more subjective account of well-being, the use of objective criteria is embedded in the enterprise of medicine. Generally speaking, the health profession focuses on establishing standards for interprofessional agreement and standards for professional obligations, so it is clear and transparent when professional duties are discharged.
imminently harmful, the health professional could include self-neglectful behavior and medical non-compliance. Self-neglectful behavior could be interpreted as all of those decisions that do not support well-being from the professional’s standpoint. The professional’s assessment of the risks and harms of the pleroma may or may not be accurate.

If a mental health professional tries to convince a patient to modify or abandon a pleroma that the professional views as unhealthy or contrary to well-being, what is being asked is significant. The patient is being asked to make a substantial sacrifice. Losing a pleroma might mean feeling adrift, alienated, isolated, and fragmented as an end-setter. The process of abandoning the pleroma and trying to adopt a new one could be painful, bitter, and terrifying. Giving up a pleroma on the advice of a physician or therapist would require a leap of faith on the part of the patient—faith that she will not end up with a mode of being that no longer feels fitting or authentic or worth its costs. Trusting an outsider to the disabled experience— the health professional with her own biases on what counts as flourishing—requires an added leap of faith. The epistemic chasm between the mental health professional and the patient cannot be understated. If the nature and gravity of this sacrifice are not recognized by the mental health professional, then building a respectful and trusting relationship may prove impossible.

**Challenges for Respecting Mental Diversity**

It still might not be compelling that there is such a thing as mental diversity, understood in terms of pleroma that revolve around psychiatrically disabled modes of being, that deserves recognition. A psychiatric disability could be considered profound because it is related to drastic
emotional episodes or because it causes diminished cognitive capacities, and I will address both of these possibilities. It is important to acknowledge that there will be psychiatric disabilities that are severe enough to make pleroma out of reach, and there are not studies to let us know the statistical frequency of pleroma in the population. However, we need to determine whether psychiatric disabilities that are profound in the ways mentioned would necessarily preclude pleroma; if not, then individuals who might be viewed as “too sick” and outside the scope of duties of recognition could instead have the standing to demand credence and respect in regards to modes of being that they find worth caring about and meaningful.

If a psychiatric disability is episodic, what the person seems to care about and find meaningful might vary drastically. Her priorities, emotional investments, and end-setting might all fluctuate. If critical interests are widened to include carings, then this problem would be framed as a tragic conflict between critical interests. The conflict is tragic because it is not clear how or if it can be resolved in any non-arbitrary way. How should we weight the competing critical interests? Are the pleroma exhibited post-episode more morally important, and if so, why? If there is a major discrepancy in pleroma when she is and is not experiencing an episode, these moral quandaries will build and become acute. It will not be obvious how best to respect the individual’s wishes or how best to advocate for her. There will seem to be two “selves” in the same person who are in disagreement about what speaks for her as an agent.

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348 By ‘critical interest’ I am referencing Ronald Dworkin’s distinction between experiential and critical interests. Jaworska criticizes Dworkin’s overly restrictive view of what counts as a critical interest; he emphasizes autonomous decision-making that is reflective of one’s narrative as a whole. Jaworska believes critical interests should be expanded to include less intellectualized forms of valuing (“Respecting the Margins of Agency” 113).

349 I am not making a metaphysical claim here; I am merely pointing out how this situation might be perceived by the individual herself or others.
One response to this proposed scenario is to deny it conceptually. Caring, according to Jaworska’s account, contributes to the unification and coherence of agency. Because of how pleroma relate to end-setting and sense of self, it is arguably not possible that a psychiatric episode would change the nucleus of her identity—if the nucleus exists at all. These episodes could make a difference for other interests or behaviors, but pleroma would persist through episodes. Pleroma can evolve and change after experience and reflection, but if the episodes are so significant as to make any alleged pleroma unstable enough to exist at one time and not at another and then reappear, then there is no actual pleroma present. Instead, what appears as pleroma are other desires and interests disguised as pleroma. So when an episodic psychiatric disability seems to be creating fissures in what someone cares about and finds meaningful, either a) the fissures are relatively superficial, and there are underlying, persisting pleroma, or b) this nucleus of her identity does not exist, and what appears to be pleroma are actually other interests with different moral obligations attached to them.

Even if it is not conceptually possible for pleroma to pop in and out of existence over a short period of time, the above response can be unsatisfactory for a couple of reasons. First, over a long enough period of time, it could be possible for someone who previously embraced a mode of being as a pleroma to abandon it but then, after reflection and exposure to other possibilities, come to embrace it again. While this would be concerning (leading us to a) or b) above) when this happens repeatedly and over, say, a week-long period, it need not be concerning if it happens over, say, a couple of months, even if these changes are associated with episodes of psychiatric disability. As long as pleroma are episodic, we are left with the problem of how to respond to these varying modes of being. Secondly, psychiatric episodes could at least affect someone’s
judgment on whether a mode of being is worth caring about or worth finding meaningful. As a result of the emotional or cognitive shifts associated with the episodes, she could come to reason about her “other life” differently. For example, she might feel bursts of creativity while in an episode, which could decrease the perceived merits of her life focused on professional rigor as an accountant. As long as her judgment about the pleroma fluctuates with the episodes, the core to her identity can seem to be in flux or always in jeopardy.

Episodic psychiatric disability need not result in drastic shifts in pleroma. It might seem to an outsider that someone does not have stable pleroma because of how her mood and personality seem to vary; in these cases, though, peripheral emotional investments could be shifting without the nuclear pleroma shifting. In other words, episodic psychiatric disabilities could lead to changes in some expressed emotions or attitudes without affecting the core of how the person views herself as an agent. If someone genuinely varies in her core pleroma, valuing one mode of being at one time and another mode of being at other times, then the moral obligations pertaining to pleroma will be relevant. These obligations could conflict depending on the frequency of the episodes and how different the pleroma are. For example, someone who experiences bursts of creativity leading to sudden traveling and fiction writing during an episode might have a career in graphic design that lends itself to creativity when not experiencing an episode; supporting the person in her identity could be accomplished by helping her pursue creative outlets, since this appears to relate to her persisting pleroma. By way of contrast, someone in an episode might experience sexual preferences that she is deeply invested in at the time, but which post-episode are shameful to her because they run contrary to her religious views and relationship preferences; supporting this sort of person in her identity would be far more
challenging, since her pleroma (if her investments amount to pleroma) seem to undermine each other.

In the case of fluctuating pleroma, one possibility is to treat such a person as different individuals at different times, for all intents and purposes, depending on which episode she is experiencing. If her pleroma do change drastically, then we should respect whatever the agent in front of us says she cares about and finds meaningful, even if we know that she fluctuates in her pleroma. This solution to the problem poses significant practical and moral concerns, however, since respecting her pleroma at one time might undermine her pleroma at another time; further, she could be mortified by her other pleroma, and she could express resentment at having those other modes of being respected.

Another possibility is to give priority to one set of pleroma over the other, even if the agent in front of us disagrees with the pleroma that are being privileged. For example, perhaps we should respect the pleroma exhibited post-episode because the episodes are relatively few and far between, which means that most of the time, these are the things that are the focus of her pleroma. Alternatively, it might be thought that the pleroma exhibited by someone while in the midst of an episode of psychiatric disability should never be privileged because the point is to nurture mental health—not psychiatric disability. These responses also have their deficits. In the former case, it is not obvious why the frequency of pleroma should make all the difference for their moral weight. If someone with full moral status cares about her mode of being and finds it meaningful, then even if she claims the opposite most of the time, there is a strong moral pull to respect her wishes and to trust her current claims all the same. In the latter case, refusing to respect a mode of being that someone cares about and finds meaningful while experiencing an
episode of psychiatric disability will be morally costly. As detailed previously, *pleroma* matter to someone’s sense of self, sense of belonging, and planning agency. If others only give weight to *pleroma* that she no longer identifies with, then she will experience enormous losses and no longer feel like herself. These feelings of inauthenticity can be detrimental on many levels, and they can feed distrust of the mental health system and others who try to intervene paternalistically with her welfare; these negative outcomes can also lead to non-compliance with treatment if the patient believes that she is being forced to try to care about things that are external or alien. Reminding her that these *pleroma* matter to her when she is not experiencing an episode may or may not be reassuring to her. If her *pleroma* really do change drastically when an episode hits, then she might feel cut off from that “other self”\(^{350}\) as much as if it were another person altogether. To the individual and to others, it might not be discernible how to hold her in her identity and discharge duties of recognition (if they apply) in these scenarios.

If a psychiatric disability leads to diminished cognitive capacities, the disability could be considered too significant for *pleroma* to be possible. The capacities for caring are far less demanding that other cognitive capacities, as described earlier, so they can endure when higher level capacities have diminished. The capacities needed to find meaning would also not be overly demanding, since finding meaning involves a relatively simple judgment: whether the agent is spending her limited time on projects that she has good reason to believe are worth the sacrifice. The person needs to know herself well enough and the nature of the sacrifice from her subjective standpoint, but finding meaning does not require that she be able to reason in detail

\(^{350}\) Again, I am remarking on her perception—not on metaphysical fact. I am remaining metaphysically agnostic on questions related to numerical identity.
through all possibilities and endorse all of her values at a higher order. Finding meaning does not require robust autonomy—that is, it does not require acting on deliberative decisions that are optimally voluntary, intentional, and with understanding. Someone could have the capacities required to find meaning in playing checkers (even poorly) with strangers in the park without having the ability to deliberate autonomously on the activity; such a person would believe that playing checkers is worth the expenditure of time and energy, though the decision could be the result of compulsion or other external influences (making it not autonomous). Together, the cognitive capacities needed for caring about something because it is meaningful are not overly demanding. Even someone with capacities diminished to an extent could be capable of pleroma. Individuals with diminished capacities might have relatively simple pleroma, but that does not denigrate the pleroma (because, as argued previously, they need not be laudable or compelling for everyone) or make them any less worthy of respect and recognition as important personal interests.

But even though the capacities for finding meaning and caring will not be overly demanding, it will be possible for a psychiatric disability to be severe enough to diminish the relevant capacities, even if they are relatively simple ones; profound fracturing can prevent someone from being able to form stable judgments, reason through decisions, or plan into the future. In a case where someone claims to find a psychiatrically disabled mode of being meaningful and worth caring about, a clinician or other person responding to this claim might worry that the individual does not have sufficient capacities for pleroma. They could suspect that the individual is reporting a mere desire, a passing whim. If it is a mere desire, then the morally appropriate response will be different than it would have been were the individual accurately
claiming a *pleroma*. Given this conundrum, there will be moral uncertainty about how best to respect the person. For example, if an accurate claim of a *pleroma* is treated as a mere desire, then moral costs could include an unwarranted paternalistic stance or unfair doubting of the agent; alternatively, if an inaccurate claim of a *pleroma* is accommodated and given recognition, it could lead to the individual being trusted and empowered in agential capacities she does not have, which might mean lost opportunities for supporting her actual moral interests.

We have moral obligations that pertain to each *pleroma* to the extent the obligations can be fulfilled. However, it is also important to emphasize that the moral obligations related to *pleroma* are not trumps or absolutes; other moral obligations, such as promoting the patient’s long-term autonomy and preventing imminent self-harm, can outweigh the moral obligation to respect and accommodate *pleroma*. In facing the moral uncertainty involved in knowing whether someone has sufficiently stable capacities for *pleroma*, we have to determine on what side to err. If what the individual wants is not contrary to other fundamental interests, then the moral costs of misjudging her capacities might not be significant. The capacities needed for any kind of valuing will lie along a spectrum, and there are no perfect instruments or indicators for ascertaining where someone lies along this spectrum.

In order to determine the morally appropriate response when someone presents with apparently episodic *pleroma* or presents with diminished capacities that cast doubt on the accuracy of *pleroma* claims, there are some steps we can take. One of the first steps is to discover what investments or commitments have been stable for her over time. Something can be stable without being meaningful for her, though, and new *pleroma* can emerge. We can search for evidence for someone’s capacity level by inquiring what she is invested in, how she reasons
through decisions, or how she reflects and adjusts her desires in light of her values. There are standard questions that are asked along these lines, but these questions tend to focus on autonomy rather than other ways of valuing. Rather than only trying to gauge if the individual has deliberated about the decision without undue influence, there also should be explicit questions about what she cares most deeply about, how her lifestyle speaks for her as an individual, how she views the core of her personal narrative, and what she believes is worth her time and efforts.

Knowing her history will also provide critical evidence, since her history can reveal what she spends her time on and what she claims to care about and find meaningful. The evidence will always be incomplete, just as we can never be wholly certain that someone is exercising her capacities for autonomy. If we have evidence on all of the above, we can have a better sense of what speaks for the agent and how her ends are structured. Participating in her epistemic perspective can make all the difference for whether this investigation into her interests is successful; other people need to be able to empathize with her emotional attunements and grasp how she is reasoning and making trade-offs. If, instead, other people steadfastly dwell in their own epistemic perspective—for example, because they have dismissed the person’s credibility as that of a “crazy person”—then they might not be able to grasp what the agent could find worth caring about or meaningful.
When someone cannot pursue what she cares about, she will experience a considerable loss; the sense of loss will be recurring and significant, not momentary or trivial. Depending on whether all of her carings are in jeopardy or only some, and depending on how central the frustrated caring is in the overall structuring of that person’s end-setting, this loss could be significantly detrimental to her identity, agency, and motivation to pursue other things of value. To be thwarted in our caring is tantamount to having our standpoint as agents disrespected. A cared-about mode of being will be referentially connected to other carings, as it will largely influence which activities and social interactions an agent invests herself in and cares about (and which she does not). We should expect this because of what modes of being are; these clusters of lifestyle behaviors and choices affect our everyday living and over-arching sense of self and belonging, as described previously.

When a cared-about mode of being is meaningful (reaches the status of pleroma), it furthermore represents what the agent has judged to be worth costs that are not recoverable. What she has invested in terms of energy and time cannot be regained after they are expended. Pleroma tie together what someone values for herself, intimately; because of how pleroma unify one’s self-told story, losing such a mode of being would disintegrate one’s sense of self. When other people, institutional forces, or external circumstances undermine a pleroma, the agent will suffer a number of deep harms that could have long-ranging effects, such as the jarring of her planning agency. Even if the mode of being does not serve her well-being in other ways, and even if she eventually comes to devalue this thwarted mode of being, she will experience these harms nonetheless.
Agents should have opportunities to discover what they do and could care about and find meaningful; they should have leeway and understanding from others as they learn what it means to care about something and discover meaning in it, even when doing so leads to negative consequences (within limits). As John Stuart Mill famously argued, we require experiments in living to determine what speaks for us as individual agents. People who are oppressed, compelled into conformity, or otherwise not given the chance to experiment will struggle to develop and understand their authentic interests. Our pleroma provide a lens for everything else that could be of value; when something runs contrary to our pleroma, it will prove difficult to find personal value in it. Even if someone’s life seems to match the idyllic picture of flourishing, those advantages and benefits will mean very little if she does not care about those things in her life or find meaning in them.

When a mode of being is associated with psychiatric disability, the accommodations for it might be relatively demanding, at least in some instances. These modes of being can fall far outside of prevailing able-minded norms, and there is an underrepresentation of these voices in frank discussions about pluralism and forms of valuable difference. A common demand among users/survivors is that they be given the resources and respect to participate in peer-run support groups on secluded farms instead of conventional psychiatric treatments in clinics or hospitals; because these groups are peer-run, current and former psychiatric patients can build a “safe” social and epistemic community that does not depend on the validation of individuals who do not have the same experiences with the mental health system.

Moral obligations of respectful responsiveness to diverse pleroma cannot be all-expansive, or else we will run into the familiar problems of medical neglect and medical
abandonment; to claim that *pleroma* have to be respected absolutely would suggest that we ought never to interfere with someone who claims to be pursuing what he or she cares about and finds meaningful (presumably with exceptions for non-trivial harms to others, such as when a *pleroma* involves violence). We do want to make the duty to respect *pleroma* a weighty one, though, since they will generally hold tremendous personal value for those who have them. Moreover, many agents will be relatively authoritative on what constitutes their *pleroma*, making any intervention to redirect it morally risky. I say that each person is *relatively* authoritative regarding his or her *pleroma* because we will often know how we are emotionally attuned, what directs our end-setting, and what we find worth investing ourselves in over time better than anyone else would be able to know; however, we could still be open to critique if we fall into self-abnegation or self-delusion, and we have to rely on our social network to remind us of who we are. But if we are generally authoritative on the content of our *pleroma*, then we should generally be granted credence when we claim a *pleroma*; additionally, if *pleroma* tend to hold the most personal value for us, then we should be given the opportunity to develop and pursue them. These obligations are *prima facie*, and they can be overridden out of consideration for harm to others and harm to self.\(^{351}\)

I will highlight three *prima facie* obligations that mental health professionals have in relation to their patients when patients have *pleroma* associated with psychiatric disabilities. These obligations include 1) giving moral weight to an expressed *pleroma* and including it in

\(^{351}\) What counts as an overriding concern for self-harm is debatable in many cases. Using an overly narrow definition of “imminent threat of bodily injury or death” has a number of problems with it, but using an overly broad definition of “anything that could put the individual in danger or at risk” has its own problems as well. I do not have space here to delve into these debates, though they will be important in many instances where health care providers (and hospital administrators and policy makers and law enforcement officials and others) need to know where their obligations lie.
therapeutic decisions, 2) creating opportunities for the fulfillment of the pleroma while the patient is in the providers’ care, and 3) facilitating the search for new meaning when a pleroma cannot or should be pursued as part of the therapeutic plan. Each of these obligations will have numerous caveats that depend on the specific circumstances of the patient and the clinical context, and the fulfillment of these obligations will have a variety of constraints. A couple of important constraints to acknowledge up front is that what is truly feasible in any clinical environment might be limited, and what is knowable (not just known) about the patients’ pleroma could also be highly limited. There will be epistemic limits with all of this, which means mental health professionals have to determine the proper moral response in the face of uncertainty. The level and contextual details of the uncertainty will make a difference for what the proper moral response is, which means that no blanket rule can be provided. I will turn to each of these broad obligations in turn.

Pleroma in Therapeutic Decisions

Under the biomedical model of mental illness, any pleroma associated with psychiatric disability will be interpreted as pathological and less than ideal. This interpretation of the pleroma challenges the patient’s knowledge and value claims. In trying to negotiate medical aims with the patient’s own therapeutic aims, health care providers and patients can run into a number of obstacles. In some cases, a pleroma associated with psychiatric disability will not pose significant problems for the patient’s other interests; at other times, the patient might want to take risks or make value trade-offs that are concerning to the mental health professional.

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Patricia Deegan, an activist and scholar with psychiatric disability, provocatively stated that “now that you have been labeled with mental illness the dignity of risk and the right to failure have been taken from you.” Patients without psychiatric disabilities are regularly permitted to make decisions that are considered medically suboptimal (though there are ethical limits on allowing patients to do this, such as when they lack decisional capacity). Deegan’s point is that patients with psychiatric disabilities should similarly be able to decide for themselves when certain risks are tolerable based on their own normative outlook. If a pleroma does not optimize all aspects of a patient’s interests, but the patient values the pleroma over these other interests, then the question arises whether it is ethically permissible to entrust the patient to make this decision. Relatedly, the mental health professional has to determine what her ethical obligations are.

One area of foreseeable contention is the prescription of psychototropic medications that have the side effect of flattened affect. If emotional attunement is deadened, then it will be difficult for patients to retain their emotional investments, including their carings. This will not only be a problem for caring about modes of being but a concern about carings, period. If a patient experiences this side effect, it would be understandable for her to refuse to comply with treatment. If every mental health professional she encounters recommends similar medications, then it would be understandable if she grew to distrust medical advice and avoided physicians.

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352 Deegan, “Recovering Out Sense of Value” 361
353 Damasio and others also provide evidence that people who have deficiencies in their secondary emotions will have significant difficulties in coordinating their activities over time, even if their reasoning abilities are intact (discussion in Jaworska, “Caring and Internality” 556).
However, from the mental health professional’s standpoint, the benefits of the medication could outweigh these concerns.

In order to proceed in an ethically responsible manner that has the best chance of recognizing difference when it ought to be recognized, the mental health professional and patient will need to establish the right kind of therapeutic relationship. When possible, they will need to decide, jointly, what the risks and benefits of the different options are, as well as how they should be weighed against one another. The patient’s well-being and autonomy interests should be part of these conversations, but the patient’s pleroma and other sources of meaning should be included as well. Shared decision-making is considered the ethical gold standard for this relationship, including in psychiatric contexts. While shared decision-making will be relatively easy to accomplish in some cases, it will be exceedingly challenging in others. The next chapter delves into these problems and proposes some solutions.

**Opportunities for Pleroma in Clinical Contexts**

While patients are in the care of health professionals during a hospitalization, they will likely have less freedom and opportunities to pursue their *pleroma*. The confines of the hospital room and unit, the absence of their chosen community, and the lack of innumerable activities and stimulation all lead to an environment that can be experienced as stifling and dull. For patients who are already concerned that they will lose valuable aspects of their mode of being as a result of medical interventions, the confines and limitations of the clinical environment can be all the more distressing. Psychiatric users/survivors highlight the ways in which they do not feel
listened to or respected by clinicians, and they attest to the vulnerability that many of them experience while hospitalized. This vulnerability and fear should be acknowledged by mental health professionals.

Carolyn Ells suggests that “the desire for control can be particularly acute when the boundaries of control are external to the person, such as when the ‘medical machinery’ takes over, leaving someone with disabilities feeling helpless and unable to control what happens to her body, self, and life.”354 She further emphasizes that loss of control is continually experienced, even in the most mundane decisions and lack of options.355 Even when patients have cognitive deficits, health care providers should try to recognize and accommodate what the patients value; Jaworska makes this point, suggesting that caregivers should try to arrange activities that fit within those values.356 To the extent possible, mental health professionals should explore ways in which patients can safely pursue their *pleroma* in the clinical environment. For example, protecting time and safe spaces for creative expression with journals, art, or performance could help some patients feel less like they are victims to “losing themselves” when hospitalized.

Having an element of peer-run support might be feasible in some facilities, so patients can adopt positions of responsibility, build affiliative bonds, and learn from each other. If nothing else, health care providers could enhance the trust in the therapeutic relationship by talking about concrete plans for pursuing the patient’s *pleroma* safely and effectively when outside the hospital (if possible). Writing out tasks and coping strategies for pursuing what the patient values can be

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354 Ells 606-607
355 Ibid. 607
356 See, for example, the case of Mrs. Rogoff, who had dementia but still valued being able to cook and host for guests. Mrs. Rogoff felt a sense of pride and self-worth in cooking tasks. Jaworska indicates that Fran, her caregiver, appropriately helped Mrs. Rogoff feel like she was contributing to cooking, and it would have been harmful and disrespectful to do otherwise (“Respecting the Margins” 119-120).
an inpatient activity that supports her *pleroma* in the long-term and helps show respect for her stated values in the meantime.

**Facilitating New Searches for Meaning**

There are several reasons why a patient with psychiatric disability might need to pursue other sources of meaning, including other *pleroma*. For example, the patient might be facing a long hospitalization\(^{357}\) or residence in a long-term care facility, thus limiting the patient’s ability to continue the pre-hospitalization *pleroma*. Alternatively, the mental health professional might believe that the patient should live out a different *pleroma* because (e.g.) the patient’s current mode of being poses significant safety concerns. In some cases, the patient will seek assistance from a mental health professional in order to break out of her current *pleroma*, hoping to find a different mode of being that suits her life in other ways. Patients living in hospitals and facilities are deeply dependent on health professionals and other caregivers for their everyday activities and constructed sense of self. As such, patients’ emotional investments will be extremely fragile if they do not receive acknowledgement and support. The development and maintenance of agency are deeply relational,\(^{358}\) and, in the same vein, capacities to discover meaning and to care are relational as well.\(^{359}\)

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\(^{357}\) Even in acute care hospitals, it is not unheard of to have patients on psychiatric units for many months of even over a year. If safe discharge or transfer options do not exist, and the courts do not demand the patient be returned to her previous location, then a patient could end up a long-time resident in a hospital.

\(^{358}\) See, for example, Barclay’s discussion of the social self.

\(^{359}\) Jaworska’s analysis of individuals with dementia make this point clear, as their identity and status as persons largely depend on how caregivers respond to them. Ells makes the point that capacities to value, control, and make authoritative decisions are interdependent for persons with disabilities. Lindemann stresses the relational and social nature of the construction of identity.
If a medical intervention only leads to the loss of a *pleroma*, the patient will likely not feel whole or healed. For the patient to walk away from the clinical encounter with a sense of identity and purpose, the mental health professional might need to go further in assisting her to find new sources of meaning. These new sources of meaning may or may not lead to *pleroma*, since *pleroma* take shape over time. The point is to help build the foundation for *pleroma* in the future. For some patients with psychiatric disabilities, this foundation will be crucial for giving them some stability and guidance as they leave the providers’ care. If the patient has other caregivers (such as family or personal care aids), then the mental health professional should work with the caregivers to facilitate the patient’s search for new sources of meaning. Jodi Halpern argues that patients might need their health care providers to assist them in finding new goals and “finding a new sense of oneself as a center of initiative and efficacy.” Along similar lines, patients who are intensely vulnerable as a result of giving up some sources of meaning in the hopes of finding others, might need mental health professionals to build the patients’ confidence, self-trust, and sense of agency. The mental health professional should help the patient feel empowered in finding new sources of meaning, including *pleroma* (at least eventually).

I have argued that *pleroma* are integral to someone’s identity. Patients with psychiatric disabilities face oppressive circumstances in many spheres of life, including aspersions on their identity. Psychiatric users/survivors argue for the right to self-definition, but patients in the vulnerable circumstances I have described might heavily rely on health care providers to assist

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360 Halpern 104. She is specifically analyzing how to recover autonomy after overwhelming grief affects a patient’s decision-making, but her argument has broader implications.
them in crafting their identity. This collaborative work does not eliminate the possibility for the patient to self-define, since the project of self-definition is never atomistic or isolated. The search for new sources of meaning goes hand-in-hand with finding a new sense of self.

The mental health professional and patient should be aware of the ways in which identities can be distorted by oppression;\textsuperscript{361} given this backdrop, the provider and patient should make a point of finding sources of meaning that are not damaging. Otherwise, this delicate moral work on the part of the provider and patient can perpetuate misrecognition. Building off the work of Charles Taylor, Hilde Lindemann argues that “a person whose identity has been damaged can be prevented by those with greater social power from fully exercising her moral agency or enjoying access to the goods that are on offer in her society.”\textsuperscript{362} This problem arises when the mental health professional tries to impose on the patient a narrow view of meaningfulness, so the patient is encouraged to find meaning only in what fits able-minded norms, even when the norms are not embraced by the patient. For example, overemphasizing the importance of intellectualized achievements and workplace productivity will have the result of alienating some patients with psychiatric disabilities, since they might not be capable of finding meaning in them.

Patients with psychiatric disabilities will vary in their vulnerabilities and sense of empowerment when trying to find sources of meaning. Health care providers can ameliorate or worsen these vulnerabilities. Lindemann analyzes the collaborative work involved in supporting someone’s identity in times of childhood and dementia. She argues that families and caregivers will be responsible for constructing and maintaining these individuals’ identities, which involves

\textsuperscript{361} Nelson
\textsuperscript{362} Lindemann, \textit{Holding and Letting Go} 109
“treating him in accordance with their narrative sense of him” and also “weeding out the stories that no longer fit and constructing new ones that do.”\textsuperscript{363} Her arguments apply to many cases of psychiatric disability as well. I have described some of the ways in which a mental health professional could overly constrain the patient in her pursuit of meaning. Properly responding to the patient will involve helping her see her future as open with possibility, so she does not feel stuck in her old mode of being and old identity.\textsuperscript{364} The mental health professional can make a significant difference for how stuck or how empowered a patient feels in this regard. Genuine collaboration in the therapeutic relationship can go some distance toward comforting the patient, understanding her viewpoint and values, and gleaning what could be meaningful to her now. What counts as genuine collaboration in mental health contexts is discussed in the next chapter.

CONCLUSIONS

This chapter philosophically unpacks the claim that someone with a psychiatric disability could value the mode of being associated with the disability. When considering the personal value that psychiatrically disabled mode of being could have, we should look beyond autonomy and well-being. By bringing caring and meaningfulness into focus, we can expand beyond this classic tension to see how these modes of being could have special importance for agents’ sense of self and sense of belonging. I argued that someone with a psychiatric disability can retain her capacities for caring about her mode of being. The complex structure of caring in its unification and continuity of agency reveals the significance of the moral interests that are at stake in

\textsuperscript{363} Ibid. 85. She calls this holding in and letting go, respectively.
\textsuperscript{364} Lindemann, “Holding One Another” 420
carings. When a mode of being is cared about because it is meaningful (a *pleroma*), it will have central importance to someone’s everyday and long-term planning agency and sense of self. As a result, there are numerous moral costs if it is threatened or lost. There are *prima facie* obligations that attend to *pleroma*, and I focused on broad obligations that mental health professionals have. The above considerations should provide beginning guidance for navigating these complex situations, so agents with non-traditional investments – such as investments in psychiatrically disabled *pleroma* – have standing in advocating for the interests that are most fundamental to their sense of self and agency. In the next chapter, I develop the notion of shared decision-making in mental health contexts. By inviting the patient as a participant in decisions, health care providers can grant interpersonal recognition and solicit the knowledge and expertise of the patient. Further clarification on knowing when and how to attempt shared decision-making is needed, and there will be significant challenges when patients present with psychiatrically disabled *pleroma*. 
CHAPTER FIVE: ACHIEVING SHARED DECISION-MAKING IN CASES OF PSYCHIATRIC DISABILITY

In the prior chapters, I show how user/survivor activism challenges standard conceptualizations of mental illness and valued modes of being. I argue that demands for recognition coming from users/survivors are similar to demands from other social justice movements, and recognition spans across public and private spheres. To achieve interpersonal recognition for individuals with psychiatric disabilities, their pleroma, as analyzed in the last chapter, should receive acknowledgement and protection as significant moral interests. Following these arguments, I attend now to a subject of intimate and immense concern of users/survivors: the therapeutic relationship. Through this relationship, individuals with psychiatric disabilities can potentially achieve interpersonal recognition. I intend my analysis to apply to a variety of relationships, including patient-physician, patient-therapist, patient-social worker, and patient-nurse. The models discussed in the bioethics literature generally focus on the patient-physician relationship because of physicians’ role in making medical treatment decisions, but other health care providers often impact how decisions are made in the course of a patient’s care, so these relationships are of concern as well. Although many models for the therapeutic relationship have been proposed over the decades, I will contribute a disability-conscious analysis that brings in insights from the psychiatric user/survivor movement. I argue that shared decision-making should be expanded to mental health contexts, but clearer normative guidance is needed for it to achieve its ethical aims. Specifically, I focus on how insight and recovery orientations can affect the very possibility of shared decision-making in mental health contexts.

I begin this chapter by providing an overview of models of the therapeutic relationship. I discuss trends toward paternalism, consumerism, and shared decision-making. I refine the notion
of shared decision-making, distinguishing it from the other models and analyzing its ethical importance. I lay out existing arguments for expanding shared decision-making to mental health contexts. I focus on those difficult cases where shared decision-making seems unreachable. While there is a push toward supported decision-making for patients with disabilities, I argue that this approach is not a model in itself, and shared decision-making remains the ethically preferable orientation in these cases. Attempts at shared decision-making in mental health contexts can err by granting patients unilateral expertise and authority, and these attempts can also err by discounting patients’ knowledge claims and recovery aims. I analyze how assessments of insight can affect a patient’s perceived epistemic standing in the decision-making process. I argue that these assessments are prone to bias and ambiguity; they should therefore have limited weight in the overall evaluation of the patient’s knowledge claims. I also show how mental health professionals and patients can come to an impasse if they do not have the same recovery orientation. Their disagreements will persist if the patient and health care professionals cannot share their expertise with one another. I thus argue that holistic recovery could involve both clinical recovery and personal recovery, incorporating the expertise and values of all parties to the decision. This chapter concludes by clarifying the normative implications of shared decision-making when this therapeutic relationship is not easily achievable in mental health contexts.
MODELS OF THE THERAPEUTIC RELATIONSHIP: FROM PATERNALISM TO CONSUMERISM TO A MIDDLE GROUND

Models of the therapeutic relationship broadly address these types of questions: What are the role-specific moral obligations of health care professionals (HCPs) in making decisions about a patient’s care? What are the responsibilities and rights of the patient in developing her own plan of care? To what extent should HCPs defer to the expertise of the patient? What kind of expertise, if any, does the patient have? If the patient’s medical well-being is in conflict with what the patient requests, how should that conflict be resolved? How should the patient’s autonomy interested be interpreted? The models provide different answers to these questions.

Ezekiel Emanuel and Linda Emanuel argue that these models are “Weberian ideals” in that they “might not describe any particular physician-patient interactions but they highlight, free from competing details, different visions of the essential characteristics of the physician-patient interaction.”365 No one model will or should govern all health care decision making. Health care decisions can be multitudinous, particularly over the course of a hospital stay. The details of the decision at hand and the ability of the patient to give meaningful input have to be weighed in each specific circumstance. The options that fall within medical standards can be limited or without meaningful differences; not all decisions regarding tests, treatment, and monitoring will make a difference for a patient’s values or preferences. To avoid creating decisional fatigue for the patient, health care providers should refrain from adding certain decisional burdens to the shoulders of patients who are already stressed and overwhelmed. Some medical decisions should

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365 Emanuel & Emanuel 2221
just be made by physicians. In a standard ICU stay, for example, the physicians will have to make a number of decisions on the patient’s behalf, such as how to treat sepsis effectively, which clinical consultants to involve, and what labs to order.

Further, all of these models can, in practice, fail to uphold ethically preferable decision-making. For one, the nuances and implications of the models can be poorly understood or poorly executed. Additionally, choosing one model over others can be based on clinical assessments of decisional capacity or court assessments of competence,\(^{366}\) both of which can be flawed. Approaching the therapeutic relationship through a singular model can lead the health care provider to overlook pertinent particularities of the patient and decision at hand. The choice of model needs to be sensitive to the details of the decision and the abilities (actual and potential) of the patient in the particular circumstance. It is no easy task for a health care professional to try to transition adeptly from one model to another; potential obstacles include the skills of the HCP, time constraints, and quality of intra-professional communication and patient hand-off.

The particular approach to the therapeutic relationship at any given point in time will need to take all of these factors into account: the patient’s ability to participate, the provider’s experience and knowledge of the relevant facts and values, the complexity of the decision, which

\(^{366}\) ‘Capacity’ and ‘competence’ are distinct terms, though they are often run together in the bioethics literature. Someone can be said to lack capacity or competence in full or in part, meaning that they are capable of making some decisions but not others. ‘Capacity’ refers to a clinical assessment about whether a patient can sufficiently understand, appreciate, reason through, and communicate a choice (Appelbaum & Grisso). Capacity is choice-specific and decision-specific, the more complex decisions requiring a higher level of capacity (Buchanan & Brock 53 ff). Capacity can fluctuate for a single patient on a single admission. In contrast, ‘competence’ refers to a legal designation of whether someone should be considered their own decision maker for health care, financial, and other decisions. Everyone over the age of 18 is presumed to be globally competent until proven otherwise; if someone is deemed incompetent by a court, it is often a global assessment that results in the assignment of a guardian for all decisions (though the guardian might be specifically empowered for health care decisions and not others, based on what is presented to the court at the time).
alternatives (if any) are available, and the potential impact of the decision for the patient’s values and preferences. A relationship is not formulaic; what ought to be prioritized or emphasized has to be fluid and dynamic as each party responds to changing details about the situation and each other. Nonetheless, modeling the therapeutic relationship can be helpful insofar as each model helps to provide normative considerations that can serve as guideposts for the involved parties. Each model sets an aspirational note: It outlines the normative principles that the parties should strive for, even if they have to veer from the preferred model due to other considerations.

Within bioethics, one model became dominant after pitfalls of other models came to light. The bioethics story here is well-known: HCPs (particularly physicians) historically adopted a paternalistic model, which has its philosophical and ethical roots in the Hippocratic Oath. This model assumes that the patient is best served by being spared information that is considered too upsetting or technical, and the HCP is in the best position to make a well-reasoned decision that is consistent with the patient’s interests. According to this model, the HCP has all of the relevant information, and the values at stake (e.g., pain/suffering, quality of life, life expectancy, tolerable burdens in relation to expected benefits) can be judged appropriately by the HCP. In the 1960s this model faced a series of challenges with the rise of individualism, national civil and political rights movements, cases of physician and researcher abuses, and the increased complexity of medical decisions with the advent of new technology.

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367 Emanuel & Emanuel; Kon
368 For discussion of the Hippocratic roots of medicine, see Pellegrino.
369 Emanuel & Emanuel; Callahan; Veatch, Patient Heal Thyself
The resulting patient self-determination movement insists on patient control, vastly reducing the role of the HCP in the clinical relationship. If the paternalistic model was on one extreme, a consumer model lay on the other. According to this model, choices should be offered menu-style to patients. Patients need the relevant information from the clinician, and the clinician should provide the medical facts in the most neutral way possible. Then patients are supposed to be the best judge of what is in their interests; the patient can better evaluate the trade-offs, risks, and potential benefits of the available treatment options.\textsuperscript{370} Even if in any given case the patient seems to be making a wrong-headed or inconsistent decision based on her own professed values, giving the patient the choice has inherent value on this model. Patients retain the moral right to make mistakes and to take risks, and HCPs should content themselves with providing clear and unbiased information. The patient’s autonomy interests (where ‘autonomy’ is conceptualized as control) are paramount on this model, and HCPs’ obligations are limited to those that facilitate the patient receiving what she wants from clinical medicine.\textsuperscript{371}

There is widespread consensus among bioethicists that the paternalism and consumerism models both misconstrue the role-based obligations of HCPs and the proper conception of patient autonomy.\textsuperscript{372} Whereas the paternalism model over-emphasizes the expertise of HCPs and mistakenly minimizes areas for reasonable disagreement regarding relevant values, the consumerism model diminishes the experiential knowledge and value competence of HCPs and overestimates patients’ ability to make well-informed decisions that serve their enduring

\textsuperscript{370} Veatch, \textit{Patient Heal Thyself}; Emanuel & Emanuel
\textsuperscript{371} Emanuel & Emanuel
\textsuperscript{372} Ibid.; President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 36
interests. Although it is possible to offer more nuanced and sophisticated versions of paternalistic and consumer-driven models, there is a general tendency in the bioethics literature since the 1980s to try to pave a path between these extremes. As a middle-ground model, shared decision-making holds out the promise of balancing the input of HCPs and patients, overcoming the weaknesses of prior models and ethically reorienting all involved parties.\(^{373}\)

Shared decision-making first appeared in the bioethics literature in the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research’s 1982 report, *Making Health Care Decisions*. In this report, they contend that “[e]thically valid consent is a process of shared decisionmaking based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments.”\(^ {374}\) Shared decision-making, the report elaborates, invites both parties to agree on a treatment plan after bringing together their different perspectives. The report focuses on how the consenting process can be improved if it follows from a trusting relationship that allows the HCP to tailor the conversation for the patient’s needs.\(^ {375}\) Input from the patient is as important as input from the provider, according to the report, since medical needs are complex and value-laden, and medical needs are only part of the picture. The report emphasizes the ethical importance of patient self-determination, and “well-being is not a concrete concept that has a single definition or that is solely within the competence of health care providers to

\(^{373}\) In analyses of the patient-physician relationship, the general presumption is that the patient is both competent (legally of age) and capacitated. But if an incapacitated patient in nonetheless able to communicate preferences and participate, should there not be similar explorations of how to approach that therapeutic relationship? I will take into account this consideration in my analysis of shared decision-making.

\(^{374}\) President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

\(^{375}\) Ibid. 36-38
define."\textsuperscript{376} This new approach to the therapeutic alliance has received substantial support since then from medical societies\textsuperscript{377} and bioethicists, eventually being incorporated in mental health contexts as well.

\textit{Refining Shared Decision-Making}

Although conceptually contested and fuzzy around the edges, shared decision-making broadly includes the following elements: recognition of dual expertise of the clinician and patient, bidirectional informational exchange, arrival at a mutually agreed on decision through collaboration, and the establishment of a trusting and respectful therapeutic alliance.\textsuperscript{378} This model does not prioritize the expertise of the HCP over that of the patient or vice versa, separating it as a model from paternalistic and consumer-driven predecessors. This model has the potential benefits of improving the quality of the decision-making process, uncovering relevant information from multiple perspectives, satisfying many patients’ desire for increased involvement in their health care, reducing patients’ stress and dissatisfaction regarding their care, increasing treatment adherence, and enhancing the therapeutic relationship.\textsuperscript{379}

Each aspect of the shared decision-making model needs clarification and refinement. The first dimension—recognition of dual expertise—is open to interpretation. One interpretation

\textsuperscript{376} Ibid. 44
\textsuperscript{377} For example, the Society of Critical Care Medicine (2016) and Massachusetts Medical Society (2014) encourage shared decision-making.
\textsuperscript{378} SAMHSA 3; Patel et al.; Légaré & Thompson-Leduc; Matthias, Salyers, & Frankel 177; Langer, Mooney, & Wills
\textsuperscript{379} SAMHSA 7, 8; Goossensen, Ziljstra, & Koopmanschap 50; Patel et al.; Mahone et al. e28; Matthias, Salyers, & Frankel 176; Langer, Mooney, & Wills
would be that the HCPs should share their medical expertise, while patients should share their value expertise. On this picture, the HCP has epistemic authority in relation to the medical facts and medical options, but the patient has epistemic authority in relation to the values and trade-offs at play. Rebecca Kukla points out that the fact-value division of labor overlooks the value-laden nature of medicine and the moral expertise that HCPs can have.\textsuperscript{380} HCPs have “lots of opportunities to think through the moral complexities of the procedures and options that make up their daily practices, whereas patients are likely confronting these complexities for the first time.”\textsuperscript{381} Additionally, patients have narrative and emotional knowledge that relate to medical options, as medicine is not a value-free or purely objective enterprise.\textsuperscript{382} The HCP should not be viewed as final arbiter of the medical facts, since the medically supportable options reflect value assumptions about what the therapeutic goals ought to be. To be successful, shared decision-making would need to include acknowledging, welcoming, and respecting different forms of expertise coming from all involved parties. This sharing of expertise should not end when developing the fundamental goals of care and formulating the medically supportable options.

Similarly, the nature of bidirectional information exchange needs to be clarified for shared decision-making to succeed. If the HCP’s role is confined to giving information for the patient to use, then the \textit{sharing} involved is rather minimal. If the patient’s knowledge claims are reduced and reframed according to biomedical modeling, then the information gleaned from the patient’s narrative and experiences will be limited. Depending on how they obtain the patient history, HCPs might only process and document the patient’s given information in terms of

\begin{itemize}
  \item \textsuperscript{380} Kukla, “How Do Patients Know?” 32
  \item \textsuperscript{381} Ibid.
  \item \textsuperscript{382} Ibid.
\end{itemize}
symptoms; the patient as a whole person can get lost in the exchange. True sharing of information requires genuine epistemic openness to what the relevant information is. If the HCP or patient becomes too stuck in her own perception of what is relevant for decision-making, then they will struggle to share in any decision. Relatedly, the involved parties need to try to be as neutral as possible in their reception of the shared information. If either views the other’s information through a narrow lens, then very little will be gained from the conversation. Given each person’s epistemic standpoint and aims in the conversation, perfect epistemic openness and neutrality are not possible. Importantly, though, each party needs to be open to learning from the other, and this learning goes back to the fundamental issue of which information is relevant for the decisions at hand. The parties involved will need to work to make their information understandable to the other, and each party in turn will need to try to understand the other’s information with humility and charity.

Arriving at a mutually agreed-on decision might be relatively simple or deeply complex. The HCP could invite a patient to participate in decisions for the sake of making the patient feel heard and gaining trust, while the HCP still intends to push for the treatment plan that the professional believes is in the patient’s interests. The interaction with the patient might not have much of a chance to change the HCP’s mind about what the therapeutic goals should be. The patient could be similarly entrenched in what options she is willing to consider. Both parties could end up striving for the path of least resistance, making easy decisions but pushing off difficult decisions in the hopes that the other will change her mind. The parties could attempt to compromise, even if the outcome is not preferred by either. Shared decision-making should not always involve compromise. Ideally, the mutually agreed-on decision will be embraced by the
involved parties, who will agree on the patient’s holistic needs and how medicine can meet those needs.

When shared decision-making is most successful, the involved parties feel respected as part of true therapeutic alliance. Patients (at least in this country) generally want to feel respected as individuals with distinctive interests and concerns. They want to be viewed as participants and not as objects to be managed, as whole persons and not as a set of problems.\footnote{Peter Strawson delineates the objective and participant stances. In the latter, the parties have equal and reciprocal interpersonal standing. He argues that suspending the participant stance could be justifiable when someone is in diminished agential state, and he includes the “hopeless schizophrenic” in this category (78). The testimony of users/survivors suggests that individuals with psychiatric disabilities meet the objective stance when it is unwarranted, leading to their feeling disrespected as persons. Although there is significant philosophical work needed on appropriate reactive attitudes towards individuals with psychiatric disabilities, I do not have the space for it here.} When patients are treated as “difficult patients,” it can compound their sense of not being cared about or trusted. HCPs want their professional integrity respected, generally meaning they want to act within medical standards with the freedom to refuse treatment options that do not cohere with those standards. HCPs often feel coerced and manipulated into therapies they do not support, and they might feel pressured to postpone necessary treatments when a patient does not want to discuss the matter.

When the other elements of shared decision-making are achieved – recognition of dual expertise, bidirectional information exchange, and arriving at a mutually agreed-on decision through collaboration—the parties to the decision are more likely to feel respected. Still, how the parties interact with one another can make a significant difference to whether they feel respected in the sharing of decisions. These interactions will be affected by tone, language choices,
physical demeanor, and level of engagement. Even if the other elements of shared decision-making have been achieved, neither party should take it for granted that the other feels respected. Ideally, the HCPs and patient should believe that the efforts needed for shared decision-making are worth it out of respect for the others, and, moreover, they should be convinced that everyone’s commitment to shared decision-making is genuine and not superficial or lackadaisical.

As a model, shared decision-making assumes sustained contact between HCPs and the patient. At times of medical emergency, this model is likely not the ethically preferable one. For other times, especially when the patient is in a more prolonged state of vulnerability and dependence on HCPs, this model should guide a variety of decisions. The goals of shared decision-making, as analyzed above, stretch beyond particular medical decisions to the relationship as a whole. The point is not to establish a respectful alliance only when a consent form needs signatures. Rebecca Kukla makes this point: “The bulk of our health care activities take the form, not of crisis management and punctate decisionmaking, but of ongoing practices, including large amounts of self-management and surveillance.”384 HCPs use their medical authority to try to influence patients’ general health care commitments that extend inside and outside clinical environments.385 To form sincere commitments that support the patient’s holistic interests over time, the patient and HCPs should build and maintain the sort of relationship that is characterized by shared decision-making. When the involved parties have an orientation toward

384 Kukla, “Conscientious Autonomy” 37. Also see Matthias 177 for a discussion of shared decision-making across the entire clinical encounter.  
385 Ibid.
When Shared Decision-Making Is Not Possible

This chapter focuses on challenging cases where shared decision-making is possible, though it might not seem so to HCPs or to the patient due to various barriers. Before moving to a deeper analysis of shared decision-making in mental health contexts and these difficult cases, I will briefly acknowledge that there are occasions when shared decision-making is not possible, no matter what efforts are made. It is important to acknowledge that shared decision-making is not a perfect or possible model for all situations, given much of the bioethical literature implicitly suggests the opposite.

Some medical conditions make it less likely that shared decision-making is possible, at least for certain decisions. For example, compulsions generally prevent a patient from being able to engage in shared decision-making on those matters that are directly related to the compulsion. The nature of the compulsion is such that the patient is often unable to process or appreciate critical information, and she might be unable to form certain health care commitments. For example, patients with drug addictions are often unable to engage in shared decision-making about their drug use. A patient with psychogenic polydipsia who compulsively drinks water from every available source will probably be unable to share in decisions related to water consumption. Some eating disorders can make shared decision-making about food choices nearly impossible. But even if the patient does not have any medical condition that would pose
problems for shared decision-making, this type of therapeutic relationship still might not be achievable for a number of reasons. For example, some patients insist on not being included in decisions. In some situations, the disagreement between the patient and HCP might be so fundamental that they will not be capable of agreeing on an option, at least at the time that this decision has to be made.

Ethically, the recommendations for how to proceed in these cases will depend on the specifics of the patient, her medical needs, and the clinical context. When a patient with decisional capacity disagrees with her physician about the preferable course of care, but what the patient prefers is within medical standards, then the physician should either comply with the request or refer the patient to a willing provider. If a capacitated patient requests a plan of care that is contrary to medical standards, then the physician should confer with colleagues about the facts, offer transfer or referral if there is interprofessional disagreement, but ultimately refuse to offer the service if the physician remains convinced that the request is not medically supportable. If the patient lacks capacity, then HCPs should work with an appropriate surrogate decision-maker to support the patient’s interests. If an incapacitated patient disagrees with the health care team about preferable treatments, the surrogate and HCPs will have to determine to what extent they should subject the patient to involuntary treatments. Concerns about a long hospitalization, complications, poor compliance with medications or post-op care, and restraint use could make some care plans ethically problematic. In some cases, an incapacitated patient will disagree with the course of care but not resist the medical interventions, and the patient’s acquiescence could justifiably lead to more paternalistic medical decisions on the patient’s behalf.
With all of this said, the guiding assumption should be that shared decision-making is possible. HCPs and patients should work to identify any barriers to shared decision-making and see how insuperable the barriers really are. Historically, most HCPs wrongly assumed that sharing in medical decisions was not really possible or appropriate, especially in psychiatric contexts. More recently, many patients wrongly assumed that HCPs have no valuable input to offer besides medical facts. By adopting shared decision-making as the guiding model for the therapeutic relationship, HCPs and patients can make it all the more likely that shared decision-making is ultimately possible, as I suggested above. Orienting themselves around this model will make the parties to the decision more likely to listen to each other, to be open to learning from one another, and to arrive at a decision together. In contexts where patients are especially vulnerable and HCPs have been invested with a great deal of paternalistic authority, as is the case in mental health contexts, this orientation has particular ethical urgency.

EXPANDING SHARED DECISION-MAKING TO MENTAL HEALTH CONTEXTS

In the last twenty years, there has been increasing scholarship endorsing shared decision-making in mental health contexts. Psychiatric disabilities are better understood, so there is wider acknowledgement that many of these patients are capable of participating in decision-making. The prominent literature on the topic tends to suggest that this model is appropriate for all patients with psychiatric disabilities, including those who have been involuntarily hospitalized. This literature often characterizes shared decision-making in consumer-driven terms, saying patients should be able to determine for themselves when and how they make their own health decisions.
care decisions. Some of the literature makes the opposite error, describing shared decision-making as occurring when the mental health professional gains a patient’s trust for the sake of securing compliance with the professional’s recommended treatment. I have already indicated that the model of shared decision-making is susceptible to consumerist and paternalistic interpretations, but a refined and robust version of it would not fall into these traps.

In this section, I first provide an overview of the existing literature on shared decision-making in mental health contexts. I analyze the most significant failures of the current literature, highlighting the ways in which shared decision-making tends to be misconstrued. I then identify some of the challenges with achieving this therapeutic relationship in certain cases of psychiatric disability. I defend shared decision-making as the ethically preferable default for the therapeutic relationship, even when the patient has less-than-ideal capacity and needs substantial supports to participate in health care decisions. I show how the literature on supported decision-making should supplement the current understanding of shared decision-making.

**Brief Overview of the Current Literature on Shared Decision-Making in Mental Health Contexts**

In 2005, the Institute of Medicine (IOM) published *Improving the Quality of Health Care for Mental and Substance-Use Conditions*, which offers the following foundational rule for patient-centered care owed to all patients: “Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences
and encourage *shared decision making.*”\(^{386}\) 

This report discusses how stigma, discrimination, and coercive practices can obstruct shared decision-making. Patients need to have a sense of meaningful agency to participate in decision-making, but over time, patients with psychiatric and substance-use conditions can come to distrust their own judgment. The report argues that “patients’ behaviors will be determined by how meaningful a given problem is to them and how capable of resolving the problem they perceive themselves to be.”\(^{387}\) The report suggests that HCPs can and should take steps to enable these patients’ participation in decision-making, which means that these patients could be more capable of shared decision-making than is commonly recognized. The IOM contends that shared decision-making should be the default for this patient population just like it is the ethical default for other patients, and, notably, the report makes this argument in regards to all types of psychiatric disability. According to the report, HCPs will have to work to reduce barriers for all patients and support them in developing confidence in their agency.\(^{388}\)

The Substance Abuse and Mental Health Services Administration (SAMHSA) published *Shared Decision-Making in Mental Health Care* in 2011, in which they also contend that shared decision-making is owed to patients with psychiatric conditions, even in cases of involuntary commitment,\(^{389}\) so as to “decrease the informational and power imbalance between the practitioner and consumer.”\(^{390}\) Their report echoes many of the points made by the IOM, such as the importance of reducing coercion and incorporating patient preferences “in the design,

\(^{386}\) Institute of Medicine 78, emphasis added
\(^{387}\) Ibid. 84
\(^{388}\) Ibid. 110 ff.
\(^{389}\) SAMHSA 13, 70-71
\(^{390}\) Ibid. 47
administration, and delivery of treatment and recovery services." SAMHSA suggests that many patients who are involuntarily committed end up having their rights to decision-making, inside and outside the hospital, violated or undermined without sufficient warrant. Capacity determinations and assessments of imminent danger (both of which are necessary for involuntary hospitalization) are open to disagreement and value considerations. The ethical requirements of patient-centered care and shared decision-making would require transparency with the patient and her family about the reasons for confinement, and evaluations of incapacity and dangerousness should be officially standardized through an inclusive and equitable process that is open to critique. The report states that psychiatric patients routinely have their epistemic testimony doubted, and involuntarily committed patients are especially vulnerable to having their perceptions of their care discounted. The report concludes by enumerating the many knowledge gaps that must be addressed for maximizing shared decision-making in mental health contexts, and involving patients in all areas of research and policy development is a necessary antidote to their history of exclusion and coercion.

Multiple studies and surveys indicate that shared decision-making can be feasible and productive in psychiatric treatment. For instance, in one of the first studies of shared decision-making among in-patients with schizophrenia, Johannes Hamann and colleagues found that decision aids and planned conversations could have a positive impact on the therapeutic relationship. Physicians and nurses reported that most of the patients in the intervention group

391 Ibid. 126
392 Ibid. 123
393 Ibid. 125
394 Ibid. 350 ff
were interested in the information and capable of understanding it. The patients who were invited to participate in treatment decisions reported that they felt more involved, knew more about their treatment and diagnosis, and had more positive attitudes toward medication. The psychiatrists reported that the shared decision-making process did not increase time spent, and the psychiatrists were more satisfied with what was achieved in the hospitalization. Although prescription decisions remained the same even with increased patient involvement, psychoeducation and socio-therapeutic interventions increased significantly for the intervention group.

In addition to receiving empirical support, shared decision-making fits with many of the aims of user/survivor activism. A representative article written by Robert Drake, Patricia Deegan (a user/survivor activist), and Charles Rapp praises shared decision-making as “consistent with foundational tenets of the consumer-survivor movement and [as] a welcome addition to recovery-based practice in mental health.” They argue that medical paternalism leaves “iatrogenic wounds” in making patients feel silenced, alone, discredited, and left with self-doubt. They view shared decision-making as a necessary corrective to paternalism, since the patient becomes an equal collaborator in the care plan. Drake et al. insist that most psychiatric patients have the capacity to make their own decisions, and surveys show that the majority of

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395 Hamann et al. 269-270
396 Ibid. 270
397 Ibid. 270-271
398 Ibid. 271
399 Drake, Deegan, and Rapp 8
400 Ibid. 9
these patients want to participate in hospitalization and medication decisions. They urge HCPs to trust the decisional abilities of psychiatric patients, to take advantage of psychiatric advance directives during periods of incapacity, and to empower patients to overcome self-doubt. These authors indicate that the nature of the therapeutic relationship can make all the difference for how effectual and informed a patient’s agency is.

Problems with the Current Understanding of Shared Decision-Making

Discerning the specific meaning of shared decision-making in mental health contexts is difficult, given some of its characterizations in the literature. The 2005 IOM report asserts that patients should be able to “exercise the degree of control they choose over health care decisions.” The IOM report also indicates that patients should be able to judge for themselves their own level of competence; the report states that patients should be able to assess their behaviors and handle any problems on their own terms, based on how capable the patients “perceive themselves to be.” The IOM’s report is consumer-driven in its description of shared decision-making, conflating the two models. Based on their recommendations, all patients should be given ultimate authority with the HCP as a mere technician, but as I detailed previously, this approach is ethically problematic, and this approach does not suggest genuine sharing in decisions.

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401 Ibid. 10. There is an upward trend over the years in the number of patients who desire participation in health care decisions, which means this preference could become even more common in the future, which underscores the importance of being able to achieve shared decision-making (see Légaré & Thompson-Leduc 282).
402 Drake, Deegan, and Rapp 11
403 IOM 78, emphasis added
404 Ibid. 84, emphasis added
The SAMHSA report rightly points out that many psychiatric patients unjustifiably lose their rights when it comes to hospitalization and coerced treatment, but their report does not draw clear distinctions between those instances when such paternalism could be warranted and when it is not. As such, the implication seems to be that HCPs should not impose their judgments on patients even in the most critical situations. If this is indeed the intended implication, then patients who are critically vulnerable might not receive medical interventions that could help stabilize them and protect their fundamental interests. The advice in this report is, at best, vague; at worst, the advice could contradict HCPs’ basic obligation to assist vulnerable patients in times of medical emergency and acute medical danger.

Physicians Jared Adams and Robert Drake say that in shared decision-making, “the practitioner becomes a consultant to the consumer, helping to provide information, to discuss options, to clarify values and preferences, and to support the consumer’s autonomy.” Based on this framing of the role-based obligations, HCPs should cater to the patient’s expressed interests and focus on the patient’s autonomy. Calling the patient a “consumer” is also suggestive; it indicates that the patient should be able to receive health care similarly to how consumers in a store are able to choose what they want with minimal interference from store clerks. Drake and Deegan quote the user/survivor movement in defending shared decision-making: “‘My body, my mind, my choice.’” Instead of emphasizing and illustrating how the HCP and patient can come together as equals in the decision-making process with their own important forms of expertise, the shared decision-making literature often focuses on giving patients control and trusting their

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405 Adams & Drake 90
406 Drake & Deegan 1007
reports in their entirety. This leaves little to no room for professional input on the needs of the patient.

In the literature, descriptions of shared decision-making also occasionally lean the other way toward paternalism. Even while inviting the patient to contribute to the decisions, the HCP could be mainly aiming toward “increased patient satisfaction and treatment compliance,” as described in a literature review on shared decision-making in psychiatric contexts.\textsuperscript{407} The HCPs could communicate information selectively for the purpose of increasing the chances that the patient will consent or assent to the intervention that the physician deems to be the best.\textsuperscript{408} This lean toward paternalism can occur even for HCPs who are intentionally trying to achieve shared decision-making; they might not realize that they have framed the conversation and options in a way that precludes much of a meaningful contribution from the patient. For psychiatric patients who prefer peer-run alternatives or maintaining their hallucinations, for example, they could recognize the failed attempts at shared decision-making even when the HCP does not recognize it. For psychiatric patients who worry collaboration with the HCP involves giving up some of their autonomy in vulnerable circumstances, they could think that “shared decision-making” will enable coerced treatment, seclusion, and hospitalization.

\textsuperscript{407} Goossensen, Ziljstra, & Koopmannschap 50
\textsuperscript{408} This is an indication of paternalism, as discussed in Emanuel & Emanuel 2221. I know some physicians who believe this informational manipulation is nearly inevitable in the consenting process.
Obstacles to Achieving Shared Decision-Making in Mental Health Contexts

The user/survivor movement helped to extend notions of patient-centered care and shared decision-making to psychiatric patient populations, though this model struggles to gain a foothold in clinical practice. Although there are ethical reasons supporting shared decision-making as a model, some acknowledged disadvantages include overwhelming patients who do not want the responsibility of active participation in difficult decision-making, contributing to patients’ decisional fatigue, and increasing the chances of poor decisions if patients’ biases cloud their judgment. The first two problems suggest that shared decision-making might not be the exclusively preferred model; how a health care provider invites a patient to participate in decision-making should be sensitive to how overwhelmed and fatigued the patient already might be. This is not to deny that under certain circumstances, shared decision-making can be the ethically preferable model even in the face of all of these problems. That is, even if the patient is overwhelmed, fatigued, or inclined to make “poor” decisions (e.g., decisions that are contrary to her medical good), inviting her to share in the decision can still be ethically justifiable.

In practice, however, shared decision-making in mental health contexts proves much more complicated to implement than suggested in the IOM publication, SAMHSA report, or other supportive articles. In a 2009 study of 352 Germany psychiatrists commenting on shared decision-making possibilities for patients with schizophrenia, researchers found that 51% of the psychiatrists claimed they implemented shared decision-making; 44% still preferred a paternalistic approach; and 5% viewed their role as fulfilling whatever the patient’s preferences

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409 Patel et al. 610; Mahone et al. e30 ff
410 SAMHSA 7; Goossensen et al. 50-51
are. The researchers found that patient factors and decision topics significantly affect whether psychiatrists believe shared decision-making is the appropriate therapeutic model for these patients. For example, when patients demonstrate disturbance of thought, depression, mania, shallow affect, and poor insight, the surveyed psychiatrists indicated they were less inclined to invite them to participate in decision-making. And whereas psychosocial decisions (such as housing and work conditions, discharge options, and psychoeducation) were considered to be prime topics for shared decision-making, medical and legal decisions (such as hospitalization options, prescriptions, diagnostic procedures, and drug screens) were generally considered unacceptable topics for patient participation.

The researchers conclude that psychiatrists tend to be more open to shared decision-making when patients are eager to participate and capable of collaboration by being well-informed and having insight into their illness, but even then, psychiatrists are inclined to restrict participation to those decision topics that seem to fit more with patient expertise. If shared decision-making is to be embraced and expanded in mental health contexts, these survey data raise a couple of worries: 1) HCPs might not attempt shared decision-making for patients who could be capable of participating but whose decisional needs are more complex, and 2) psychiatrists seem averse to including patients in many of the decisions that patients may reasonably care most about – those related to treatment.

This study gives evidence that shared decision-making is mainly attempted when implementing this model is relatively uncomplicated. Patients who already want to participate,
do not dispute their diagnosis, do not reject the given medical information, and do not have
negative emotional symptoms are more likely to be invited to share in decisions. If the patient is
more challenging, then a more paternalistic response might appear justifiable. Can shared
decision-making proceed if a patient struggles to make her expertise intelligible to HCPs? What
about patients who do not seem to retain or understand the medical information? When patients
believe that the mental health professionals are fundamentally wrong about the nature of their
disability, how do they attempt shared decision-making? As the IOM and SAMHSA reports
point out, stigma and stereotype can be internalized by individuals diagnosed with psychiatric
disabilities, which can lead to decreased self-esteem and self-trust. As a result of doubting their
own testimony and values, many of these patients might not feel confident or safe in initiating
shared decision-making. The HCPs could, in turn, presume that these patients are not interested
in or capable of shared decision-making.

The normative implications of shared decision-making become especially tricky to
discern in these cases where there are various barriers to genuine collaboration with the patient.
HCPs and patients might be too quick to give up on the possibility of shared decision-making
because of these barriers. HCPs might not realize the agential possibilities and deeply held
values of these patients, and the patients might not trust that they can participate in decision-
making and disclose what matters most to them. Especially given the susceptibility of the shared
decision-making model to collapse into consumerism or paternalism (as described above), HCPs
and patients might be wary to attempt genuine collaboration when they meet various hurdles.
Shared decision-making presents a crucial opportunity for improving clinical outcomes on patients’ own terms and making psychiatric patients feel safe and respected in these encounters. If executed successfully, this model can make some headway toward interpersonal recognition in health care contexts, which could have profound implications for these patients’ overall sense of agency over their bodies and behavior. Shared decision-making provides a framework that can be responsive to the patient’s capacity status, emotional states, and values – including any fluctuations. For patients with certain kinds of psychiatric disability, this attunement is critical. By inviting the patient to share her narrative and emotional knowledge, share information, and reason through decisions together, HCPs can better understand the patient’s abilities to participate in shared decision-making in and across psychiatric episodes.

Through this sustained relationship built around shared decision-making, mental health professionals can have important insight into the patient’s most enduring values if the psychiatric disability leads to fluctuations in mentation and emotionality. We cannot escape the fact that some psychiatric disabilities can impair a patient’s ability to be a successful self-advocate. In many cases, if a mental health professional is going to be morally authorized to intervene (to different degrees) with the patient’s decision-making for the sake of preserving the patient’s long-term autonomy interests, self-identified sources of meaning, or fundamental well-being, then the professional will need to do more than merely cater to the patient’s expressed preferences or unilaterally impose medical values on the patient. The orientation of shared decision-making will help HCPs support patients’ holistic interests and understand their enduring
values, including, perhaps, any *pleroma* associated with the psychiatric disability that the patient wants respected.

When faced with difficult situations where shared decision-making seems unachievable, one solution is to turn to *supported* decision-making as a model instead. Since the 2008 Convention on the Rights of Persons with Disabilities (CRPD), there has been a shift toward supported decision making for persons with physical, intellectual, and psychiatric disabilities. Article 12 of the CRPD states: “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” In response to this statement in the CRPD, some scholars and disability groups emphasize that individuals with disabilities should have the ultimate authority and responsibility for making health care decisions, which requires supported decision-making over other models, even over shared decision-making. Whereas shared decision-making “enables an individual to exercise partial autonomy over decisions” through collaboration with the HCP, supported decision-making makes it so the “individual is always the primary decision maker.” In a recent JAMA Psychiatry editorial, Graham Thornicroft and Claire Henderson interpret the CRPD as saying that “substitute decision making (which is the essence of compulsory treatment decisions by psychiatrists) is not allowed.” If the CRPD should be interpreted this way, then there is foundation for a human rights argument against compulsory treatment—an argument that many users/survivors and anti-psychiatry scholars have made for decades.

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413 United Nations Article 12
414 Pathare & Shield 4
415 Thornicroft & Henderson E1, parenthetical comment in original
For many disability groups and users/survivors, the move toward supported decision-making will be hailed as a moral victory. Implementation of this model could potentially prevent the unwarranted removal of decision-making authority from patients and instead support patients in the decisional abilities they have. To employ this approach, the HCP first needs to trust that the patient could be capable of making her own decisions with the necessary supports. This model encourages intensive and creative work on the part of the HCP to enable the patient’s decision-making capacity. A patient could seem incapacitated/incompetent on an initial assessment, but changing the environment, providing decisional supports, and establishing a trusting rapport can make it more likely that a patient can contribute to decision-making.

With all of this said, however, there are two interrelated problems with supported decision-making as a model: its inapplicability to patients who lack capacity/competence and its susceptibility to consumerism. First, some patients with intellectual or psychiatric impairment will be incapable of making decisions because of the nature of the impairment, and yet this limitation of the supported decision-making model is generally neglected. Some individuals with profound psychiatric impairments will not have the ability to contribute meaningfully to decisions, no matter how much support and guidance are offered. Secondly, supported decision-

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416 Following their 2013 symposium, Quality Trust for Individuals with Disabilities, the Council on Quality and Leadership, and the Burton Blatt Institute published a report on supported decision-making that does not even mention the possibility that the model would not apply for patients who lack capacity/competence. See their report, Supported Decision-Making: An Agenda for Action. A recent legal review of supported decision-making concludes that for a person with psychiatric disability who lacks decisional capacity, “support measures must be in place to provide all information and guidance necessary to support that person to make an autonomous decision”, as if autonomous capacities can never be impaired (Pathe & Shields 26, emphasis added).
making does not differ significantly from consumerism; it defaults to the patient’s preferences and the patient’s autonomy, reducing the role of the HCP to facilitating patient choice.

For all of the reasons given above, shared decision-making is the ethically preferable model for the therapeutic relationship in mental health contexts. This model has the potential to achieve the moral aims desired by users/survivors. The literature on supported decision-making can help enhance our understanding of how shared decision-making can respect persons with disabilities. For example, HCPs should not presume that patients with psychiatric impairments are necessarily incapable of making meaningful contributions to decision-making. As with other patients, their ability to engage in a therapeutic alliance will largely depend on whether they are enabled and supported. HCPs should invite these patients to contribute to decisions, even when the patients do not assert themselves; given the marginalization and discomfort that many individuals with psychiatric disabilities feel in clinical contexts, this encouragement is an important step toward establishing the right kind of therapeutic relationship. There should be increased research and implementation of decision aids that are tailored for psychiatric patient populations. For shared decision-making, the goal is not to put the patient in the driver’s seat alone. The point is to bolster the patient’s self-confidence, self-trust, and epistemic agency enough that she can participate in decision-making with HCPs. Thus, for shared decision-making to get off the ground as a possibility in mental health contexts, patients with psychiatric disabilities often need adequate decisional supports and assistance from their HCP.417

417 The need for decisional supports and assistance from HCPs is not unique to patients with psychiatric disabilities. All patients need this to some extent, as described by numerous bioethicists (see Beauchamp & Childress 103, 118; Nelson; Kukla, “How Do Patients Know?” and “Conscientious Autonomy”).
RECOMMENDATIONS FOR ACHIEVING SHARED DECISION-MAKING IN CHALLENGING CASES

Shared decision-making holds out the promise for interpersonal recognition by welcoming the patient as a partner in the exchange of expertise and knowledge. As such, it is worth defending. We need a conception of shared decision-making that leads to empowering patients in the right way and to the right extent. Building a relationship around shared decision-making can be especially challenging in mental health contexts. Definitionally, shared decision-making includes coming to a mutually agreed-on decision. For patients and HCPs who experience deep sources of conflict, this agreement might always seem out of reach. For patients with psychiatric disabilities, there are a couple of reasons why disagreement could persist: a) the HCP does not trust the patient’s claimed knowledge and expertise, and b) the patient and HCP have different conceptions of psychiatric recovery. If the patient’s epistemic standing and/or conception of recovery are doubted, then attempts at shared decision-making could give way to paternalism. If the patient’s knowledge claims and recovery goals are given priority over the medical expertise of the HCP, then shared decision-making can become a form of consumerism and lead to medical neglect.\textsuperscript{418} If the patient’s epistemic standing and recovery aims remain vague or unknown, then neither party to the decision-making process will have a good grasp on how to proceed in the relationship. Therefore, if these two issues can be addressed with more

\textsuperscript{418} ‘Medical negligence’ is a legal term that can apply to physicians when they deviate from standards of medical care. Even if an action or omission cannot be legally prosecuted as medical negligence, morally it can be an apt term when a health professional neglects basic duties of care or rescue for a patient in need of the expertise and resources that the professional possesses.
precision without neglecting the perspectives from the medical profession or patients, then we are a couple of steps closer to clarifying the meaning and implications of shared decision-making in mental health contexts.

**Epistemic Standing and Insight Evaluations**

In chapter three, I explore how judgments of a patient’s insight can make a significant difference to whether she is taken seriously as an epistemic agent, which has implications for epistemic injustice and misrecognition. Insight evaluations can pose a problem for shared decision-making as well. The literature on shared decision-making assumes that the patient is mentally capable of understanding and contextualizing the relevant information. If the patient rejects the mental illness diagnosis or surrounding language, refuses to accept that psychiatric medication could provide benefit, or challenges biomedical modeling of the condition, then the patient could be labeled as lacking insight. If anyone on the treating team believes that the patient has partial or poor insight, then there could be concerns with trusting the patient with decision-making. As a result, whether a patient is labeled as having insight could make a difference for the (in)voluntariness of hospitalization, guardianship and capacity evaluations, discharge decisions and instructions, and administration of oral versus long-term depot medications.⁴¹⁹

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⁴¹⁹ Casher & Bess. There are psychotherapy approaches referred to as ‘insight-oriented therapy,’ which assumes that a patient’s disordered behavior results from lack of awareness of her motivations. This form of therapy has a long history, though it faces mounting challenges due to demands for more efficient therapeutic methods (Scaturo 155). Throughout my discussion, ‘insight’ refers to a determination that mental health professionals believe is generally relevant in the clinical evaluation, regardless of their therapeutic approach, and awareness of motivations may or
In a 2011 focus group study, Irma Mahone and colleagues found that mental health professionals consider lack of insight to be a substantial barrier to attempting shared decision-making. As one provider put it: “‘[poor] insight is not accepting that you even need to be in the office, meeting with the provider at that time, because you have nothing wrong with you, so why should you even be there?’”420 If judged to have poor or partial insight, the HCP could conclude that any relationship with the patient will be challenging and strained – not conducive to shared decision-making. In response, Drake and Deegan object to “the circular reasoning that often occurs in clinical situations: When the client is compliant, shared decision making is a virtue; when there is disagreement about treatment, the client ‘lacks insight’ and shared decision making is at risk.”421

There is a deep conundrum here: Some patients will be incapable of understanding their psychiatric condition, no matter how it is framed or interpreted, which could make genuine shared decision-making unattainable. These patients might nonetheless insist that they be given decisional control. Other patients could be unjustly excluded from shared decision-making as a result of insight evaluations that prove to be problematic. I will focus on the second half of this conundrum, since my focus is on providing normative guidance when shared decision-making is possible.

First, over-idealizing self-awareness or self-knowledge can easily occur, especially when the conceptual confines of ‘insight’ are left vague. For example, it is unclear what threshold

may not be considered. I am not directly commenting on insight-oriented therapy, though a number of the issues I raise will be relevant for it as well.

420 Mahone et al. e32
421 Drake & Deegan 1007
patients need to meet to show that they sufficiently grasp and buy into biomedical discourse and understand the different features of their mental phenomena. For example, in his seminal work on this topic, Anthony David remarks that a patient who refuses to consider herself as “mad” and does not acknowledge “which elements of the disorder are fundamental to the illness category” has partial insight “at best.” Karl Jaspers says that proper insight requires an accurate judgment of the type and severity of illness and the impact of each individual symptom, and yet he recognizes that intelligence and education of the patient would be highly relevant to whether she were ever capable of achieving insight. In a similar vein, Ivana Marková and German Berrios contend that patients with insight have to know facts about their illness and understand how the illness affects them as a person. What sorts of facts should patients be able to recite? What if those facts are disputable or at least not cut-and-dry? Which consequences or factors do they need to be aware of in order to understand sufficiently how the illness affects them as a person? Does insight demand that they be able to engage in a “what-if” scenario, imagining how their personalities and behaviors and relationships would be different if they had different mental phenomena and motivations and desires? Marková and Berrios admit that complete insight on their account would require that patients receive a great deal of training.

These oft-cited conceptualizations of ‘insight’ are too demanding, as stated, to set reasonable thresholds for what clinicians should care about or expect of patients in this regard. If the criteria for insight are explicitly or implicitly over-idealized, then false negatives are foreseeable. As a result, an unnecessary number of patients will be subjected to increased

422 David 801
423 Translation in Marková & Berrios 851; also see Marková 30
424 Marková & Berrios 856
425 Ibid.
scrutiny and paternalistic interferences. Because there are no set clinical tools for measuring insight, and insight documentation in charts tends to be sparse, a patient could have very different experiences of being trusted as a decision-maker across hospitalizations or clinic visits; this inconsistency can make patients reasonably wary and distrustful of providers’ stance toward them.

In addition, standards for insight tend to privilege the knowledge and expertise of the HCP over that of the patient. Patrick McGorry and Scott McConville point out that the “assessment of insight is substantially a judgment of discrepancy between the perspective of a clinician and that of a patient”. Liliana Dell’Osso and colleagues characterize insight as judging her experiences “to be pathological in a manner that is congruent with the judgement of the involved treating psychiatrist”. They make clear that the patient has to agree with this particular psychiatrist. This stipulation assumes an ideal physician-patient relationship where the physician has unassailable expertise; lack of mutual respect or trust, imperfect information gathering or interviewing on the part of clinician, and personal dislike can all taint the relationship between patient and psychiatrist. Especially when the relationship is less than ideal, the patient might disagree with the treating psychiatrist for any number of reasons, and these disagreements do not necessarily indicate anything at all about the patient’s understanding of her condition.

426 Casher & Bess. This fits my own experience reviewing inpatient charts in multiple hospitals.
427 McGory & McConville 132
428 Dell’Osso et al. 315
Amador and colleagues famously say that in the case of poor insight, the patient’s “perception of himself is grossly at odds with that of his community and culture.” Marková and Berrios concede that insight ends up getting defined “as social acquiescence.” The worry emerges that to be considered as having insight, patients need to accept prevailing cultural norms and constructs about what their mental phenomena mean. This problem of insight is significant, since patients might have contrary views of their mental states for a variety of reasons. For example, their own cultural views and religious commitments could shape their interpretation of their mental and medical conditions. Multiple studies suggest that sociocultural biases enter into assessments of insight, given that privileged ethnic, racial, and socioeconomic groups tend to be given higher insight scores.

Further, standards of insight seem to demand that patients accept the biomedical modeling of their mental condition, labeling it as pathological while acknowledging the benefit and importance of standard treatment. Patients might reject biomedical modeling because they refuse to use associated stigmatizing language (e.g., sick, ill, dysfunctional); alternatively, they might prefer social models of mental illness. Patients might also be aware of the generally contentious nature of diagnostic categorization, especially since published concerns about the DSM’s methodology, precision, and embedded biases are readily available. Criticisms of standard psychiatric treatments (e.g., psychotropic medications, electroconvulsive therapy) are also widely published and easily accessible to patients, which can be further cause for dissension.

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429 Amador et al. 114
430 Marková & Berrios 854
431 Amador & Kronengold 8
432 Tranulis et al. 228; Reimer, “Treatment Adherence in the Absence of Insight” 73; Radden, “Recognition Rights”
433 Tranulis et al. 228; Thachuk
Given the expectations fostered by the amorphous goal of insight, a patient is best served by regurgitating jargon and phrases heard in therapy or the hospital, since this repetition most clearly indicates agreement with the treating clinician.\textsuperscript{434} Of course, regurgitation of jargon does not reveal genuine or deep agreement, and patients should not be pressured to report their experiences in this artificial and inauthentic manner. The hope or expectation that patients will come to view their mental phenomena and behaviors in roughly the same way as the treating psychiatrist ignores the possibility that the patient could have good reasons for viewing them differently. Establishing a therapeutic alliance is not best served by pressuring patients to accept their psychiatrist’s vocabulary and modeling.

All of these problems with insight determinations are concerning if psychiatric patients are to achieve interpersonal recognition in the clinical encounter. While some patients will have sufficient understanding of their condition and be able to participate in decision-making, other patients will need assistance in developing clinical insight. Psychiatric interventions generally do not merely aim at standard health outcomes (e.g., reduction in pain, distress); they also try to support and promote the long-term functional agency of patients. Patients need to be able to take stock of their desires, wants, and values, and they need to be able to predict the effects of their condition on future agency. Marga Reimer highlights the “practitioner’s dilemma”: Encouraging patients with poor insight to accept biomedical modeling and psychiatric treatments framed within that model could alienate patients and backfire; however, allowing patients to devise non-medical interpretations of their condition while accepting medical treatments seems to be

\textsuperscript{434} McGorry & McConville 134
fostering uninformed consent (or assent or mere compliance).\(^{435}\) Either way, helping patients develop insight does not necessarily lead to genuine shared decision-making.

To improve the chances of genuine shared decision-making in mental health contexts, insight evaluations should be nuanced and dynamic. More conceptual clarity and standards for assessing insight in clinical settings\(^{436}\) are needed, as well as more detailed documentation in the chart. Care needs to be taken not to misconstrue what patients do and do not understand. The first step is recognizing that reasonable interpretations of behaviors and mental phenomena do not necessarily fit biomedical modeling. These other perspectives could be informed by numerous factors, such as the patient’s personal experiences, culture, and religion. Illness language need not be embraced by the patient; if the clinician believes that medical treatment will actually benefit the patient from the patient’s viewpoint, then the clinician should recommend it while using neutral language that is amenable to the patient’s worldview.\(^{437}\) Reframing treatment recommendations in this manner need not involve deceptive or misleading claims, since biomedical modeling is not the only acceptable way to model these conditions.

When trying to navigate possible discrepancies in understanding, the HCP should consider the perspectives of the patient’s more focal epistemic community. The patient could have other people in her life who can assist the HCP in bridging any knowledge gaps that could exist on either side. A 2008 study found that patients with psychosis who lack insight on standard measures nonetheless make meaning of their experiences, and their friends and family

\(^{435}\) Reimer, “Reflections on Insight” 85  
\(^{436}\) There are instruments for measuring insight in research settings, but they are not regularly used in clinical settings, and they are not built for that purpose. See Amador & Kronenhold 13.  
\(^{437}\) Reimer makes a similar recommendation (“Treatment Adherence” 73).
tend to corroborate the patient’s narrative. This finding further suggests that these patients have not lost their epistemic community altogether, which means HCPs could potentially engage in the elements of shared decision-making (e.g., bidirectional information exchange) with these patients through creative means. The better the provider can understand the patient’s emotional and narrative knowledge, the more each party can come to understand and trust each other’s standing in the therapeutic relationship. The aim is to help the parties to the relationship feel less epistemically isolated from each other. Ideally, an insight evaluation would only occur after the mental health professional had been able to make creative attempts to close the epistemic distance between herself and the patient. This point has resonance with the Disability Rights Movement, which emphasizes the epistemic barriers that exist between those who have never experienced certain types of disability and those who have.

Currently, insight evaluations carry high stakes, which means that any error could have significant negative consequences for patients. The “poor insight” label can reinforce stigmas and stereotypes without the HCPs being aware of how it affects their perception of the patient. When HCPs evaluate a patient as lacking insight, the patient might be informally referred to as a “difficult” patient. Patients referred to as “difficult” can face strained relationships and miss opportunities to make their perspectives known. All in all, the designation of “poor insight” in a patient’s chart can lead to a cycle of paternalism if not scrutinized carefully. For all of these reasons, insight evaluations should not be given too much weight in the overall clinical judgment of the patient. A patient’s designated insight status should not serve as the sole basis for a stance

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438 Tranulis et al. 237
439 See Fiester’s analysis of the “difficult patient” label.
of preemptive paternalism, even if ‘insight’ as a clinical term were rid of its problematic ambiguities. Instead, insight evaluations should be as granular as possible and open to revision as the provider comes to understand the patient’s epistemic vantage point more clearly. These changes to insight evaluations will help facilitate shared decision-making for many psychiatric patients who would otherwise be excluded as participants.

**The Impact of Recovery Orientation**

For shared decision-making to succeed, it must be possible for the HCP and patient to agree on what the therapeutic goals ought to be. The therapeutic goals reflect values and priorities: What parts of the patient’s condition are distressing or harmful? What counts as harm that falls within the purview of a medical professional? Which treatments or therapies should be pursued? What trade-offs to health are permissible? Although the HCP and patient could come to agree on answers to these questions, they could come to an impasse if some or all of their answers diverge. When confronted with an impasse, HCPs have to decide, given their professional and ethical responsibilities, whether to adjust the therapeutic goals or to take a more paternalistic approach. This problem gets at the heart of the real-world challenges in achieving shared decision-making in mental health contexts.

In the 2015 Oxford Handbook, *Shared Decision-Making for Treatment Planning in Mental Health Care*, the authors emphasize how value discrepancies can thwart shared decision-making: ‘‘Getting better’ may be a common treatment goal, but ‘better’ likely has different meanings for different patients […] This may be especially true in mental health treatment, when
‘recovery’ may mean a reduction of symptoms, improvement of functioning in the presence of symptoms, or some combination of both.” Asking the patient what “getting better” means to her would be a step in the right direction; this question elicits the patient’s values and overall perspective on her condition, and it can signal when an impasse is looming. The patient could explicitly state that some symptoms are troubling while others are valued. For example, a patient might want to have less general anxiety and stress, but the patient might not want to lose auditory hallucinations that are experienced as comforting. Figuring out how to weigh this sort of trade-off can be challenging if the HCP believes that the more responsible treatment would be one that eliminated the hallucinations. The patient’s statement of values does not determine the issue; sharing in the decision means that other health values and priorities are relevant as well. To begin to navigate these types of disagreements, it is useful to consider different recovery orientations.

In the literature, two main camps on what it means to “get better” have emerged: clinical recovery and personal recovery. Clinical recovery (CR) represents the “traditional understanding in the mental health system of recovery as socially valued outcomes, particularly symptom remission or alleviation and relatively independent functioning”.

This view of recovery is consistent with biomedical modeling of psychiatric disability. The goal is for a patient to be in remission from behaviors and thoughts that are viewed as disabling, dysfunctional, painful, and unstable. On this understanding of recovery, clinicians promote “improvements in psychological

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440 Langer, Mooney, & Willis n.pg.
441 Slade 78
and cognitive functioning and reduction of symptoms in psychiatric illness in a way that is consistent with traditional concepts of remission in physical illness.”

One implication of this approach to recovery is that the patient’s subjective values related to his/her condition only factor into therapeutic planning to the extent that they assist communication or make (e.g.) independent functioning more likely. Any part of the patient’s perspective that seems irrelevant or contrary to those traditionally valued outcomes would be excluded from therapeutic goal-setting. Another implication is that certain people would be considered incapable of recovery; certain psychiatric disabilities do not go into remission based on the indicators of symptom alleviation and normal functioning. Additionally, a patient who valued her symptoms or devalued symptom alleviation would appear not to want to be in recovery. This conclusion in itself could potentially lead to paternalistic measures and assumptions of poor insight.

Personal recovery (PR), by contrast, is a more holistic process that is a gradual and multidimensional struggle. William Anthony formulated the leading conception of PR by synthesizing the work of users/survivors: “Recovery is described as a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with the limitations caused by illness.” On this account, recovery will involve overcoming social obstacles such as the negative effects of stigma. Symptom alleviation would be neither necessary nor sufficient to be in recovery, since

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442 Davidson, Lawless, & Leary 665
443 Slade 2012, 86
444 Anthony 1994, 527
the symptoms might not be hindering the person from successful end-setting, happiness, or meaning-making. Anthony states that recovery “does not mean that the suffering has disappeared, all the symptoms removed, and/or the functioning completely restored”. This view of recovery emphasizes subjective perspective and personal meaning-making—in contrast with biomedical interpretations of psychiatric disability. This view of recovery fits more of a social or interactionist model of psychiatric disability. Recovery extends “to include such dimensions as self-esteem, adjustment to disability, empowerment, and self-determination.”

SAMHSA characterizes multi-dimensional PR as self-directed, individualized and person-centered, empowering, holistic, non-linear, strength-based, integrated with peer support, focused on respect, based in responsibility, and supportive of hope. The focus is on being in recovery instead of being recovered or cured. Peer-run services would be crucial for staying in recovery on this view, since social supports are necessary to overcome obstacles to the above listed dimensions, such as those posed by “sanism,” and stigma. SAMHSA acknowledges that recovery “involves finding and building mutual support communities and cultures that provide a ‘sense of belonging, supportive relationships, valued roles, and community’ where people can ‘collectively and effectively speak for themselves about their needs, wants, desires, and aspirations.’” Establishing a community of choice is then fundamental to being in recovery.

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445 Ibid. 525
446 Cf. Davidson, Lawless, & Leary 2005
447 Anthony 1994, 528
448 Discussed in SAMHSA 45 and Lewis 146
449 Qtd. in Lewis 147
450 Friedman distinguishes found communities from communities of choice. Whereas found communities are given to us by birth and are often steeped in oppressive practices, communities of choice offer “contexts in which to relocate and renegotiate the various constituents of our identities” (95).
This change in orientation from clinical recovery to personal recovery has been called a paradigm shift for how to view the nature of mental illness, along with the prognosis and possibilities for those diagnosed with mental illness.\textsuperscript{451} For some in the psychiatric user/survivor movement, Anthony’s conception of PR matches their central activist aims. However, Anthony’s stress on accepting the limitations caused by illness would be challenged by many of the leading user/survivor groups like Mad Pride and Icarus Project. Instead, these groups want individuals with psychiatric disabilities to feel free to embrace their idiosyncrasies without necessarily seeing them as limitations. The personal recovery orientation does not need to be conceptually confined to flourishing despite disability; rather, it could be expanded to include flourishing in virtue of the disability.

Through the lens of “generative madness,” psychiatric disabilities are interpreted in a way that runs “against the grain of most clinical models because they frame psychic difference as something positive rather than something negative.”\textsuperscript{452} From a generative perspective, conditions that are clinically viewed as mental illnesses can be personally viewed as sources of personal identity, creativity, expressiveness, religious and spiritual experience, and social and political responsiveness.\textsuperscript{453} Recovery can be possible even for those who reject traditional biomedical interpretations of their condition and who value their symptoms. In this way, the generative view also coheres with social and interactionist modeling of psychiatric disability. Instead of learning to live with limitation, they want to cultivate these modes of being and find support in doing so. The limitations purportedly inherent in their condition need not be viewed as such; what is

\textsuperscript{451} Lewis 146
\textsuperscript{452} Lewis 145, emphasis in original
\textsuperscript{453} Ibid. 155-158
limiting to others can be generative for them, and not all social and behavioral limitations are pathological or personally troubling. Awareness of one’s condition need not involve recognition of any form of dysfunction or suffering associated with it; it can be an outright rejection of seeing limitation as inherent to psychiatric disability.454

If the patient and HCP have the same recovery orientation, then they could potentially agree on a care plan.455 But if the HCP enters the relationship hoping to accomplish clinical recovery for the patient, while the patient seeks personal recovery, this disagreement could lead to irreconcilable differences. Understanding the nature of the disagreement is the first step. As far as next steps go, I see two ways to try to resolve the conflict in an attempt to achieve shared decision-making.456 One way is for the HCP to rely on a capacity evaluation to settle the matter. Another way forward is to bridge these recovery orientations, so they are not mutually exclusive at all junctures. I will discuss these two paths, arguing that the latter is a more promising route for making shared decision-making possible.

The HCP might try to resolve the conflict by assessing the patient’s decisional capacity—that is, by evaluating whether the patient can sufficiently understand, reason through, appreciate, and communicate a stable choice.457 If the HCP evaluates the patient to have sufficient capacity for health care decisions, the HCP might be inclined to defer to the patient’s personal recovery

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454 As mentioned in other chapters, it is problematic if this claim is supposed to cover all forms of psychiatric disability
455 Of course, a patient and HCP could have the same recovery orientation but nonetheless disagree on the specifics of the care plan. I am focusing on what I see to be a deeper source of disagreement – when they do not share the same recovery orientation.
456 While referral to another provider is sometimes an option, this will not always resolve the issue. For one, referral is often not possible for patients who are hospitalized for psychiatric reasons. For another, even if the patient were referred, the new provider could have the same approach to recovery as the other provider.
457 Appelbaum & Grisso
aims. If the HCP assesses the patient as lacking capacity, then the HCP might instead push for goals that are consistent with clinical recovery (through paternalistic means if necessary). There are three main problems with this approach to resolving this type of conflict. For one, the capacity evaluation will generally start from the clinical recovery orientation. Capacity evaluations are not purely neutral; when a patient is tested for understanding and appreciation of a medical decision, HCPs (due to their training) often default toward biomedical interpretations of the condition with a bias toward standard treatment options. If a patient rejects a biomedical interpretation of her disability and rejects symptom alleviation as a goal, then the patient is vulnerable to assessments of poor insight and incapacity. Moreover, the resolution process described above is not shared decision-making. It states that if a patient has capacity, then the HCP defers to patient preferences, which most closely resembles consumerism. If the patient lacks capacity, then the HCP overrides patient preferences by pushing toward clinical recovery, which is paternalistic. We are trying to see if shared decision-making can survive conflicts in recovery orientation.

Lastly, a problem with this approach is that it presupposes the patient needs capacity to make relevant judgments about what it means to get better. In other words, if capacity evaluations are supposed to settle the conflict, then the assumption is that only capacitiated patients can meaningfully contribute to a recovery discussion as part of shared decision-making. When a patient lacks capacity, the implication is that she should not be given decisional authority; the patient needs the added protection of a surrogate decision maker (usually a partner or family member) who can make decisions consistent with the patient’s interests. But even if a surrogate should be part of the deliberation process, this does not mean that the patient has
nothing to contribute. Capacity assessments are supposed to track, roughly, the patient’s ability
to make autonomous decisions (that is, deliberative decisions that are made with understanding,
intentionality, and voluntariness). As we saw in chapter four, a patient could care about her
mode of being and find it meaningful, even if the patient lacks the ability to make autonomous
decisions. The cognitive capabilities needed for autonomous decision-making are not the same as
those needed for caring and finding meaning in a mode of being. If pleroma have moral weight,
as I argued in the last chapter, then these should be shared in the therapeutic relationship. Any
patient who is capable of pleroma should be invited to participate in shared decision-making,
even if the relationship is tripartite in including the surrogate as well.

Rather than rely on capacity evaluations in these cases of conflict, HCPs and patients can
have the most hope of achieving shared decision-making if they can creatively bridge their
recovery orientations. Clinical recovery and personal recovery are not necessarily mutually
exclusive because they can target different aspects of a disability. Just as with physical disability,
there can be components of a psychiatric condition that should be ameliorated (e.g., those that
cause pain and everyday difficulties) even if the condition, as a whole, is not devalued by the
individual. This is because disabilities are often complex in nature; they are multidimensional
with some of those dimensions being of more value to the person’s identity and mode of being
than others. Regardless of the patient’s capacity status, she could be capable of caring about and

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458 Beauchamp & Childress 101
459 Note that I am not arguing that capacity evaluations are irrelevant to the shared decision-making process. My
argument is narrower – that HCPs should not rely on capacity evaluations to determine the right course in cases of
conflict over therapeutic goal-setting.

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finding meaning in the mode of being associated with the psychiatric disability. As long as the patient is able to share this with the HCP, the patient can contribute to shared decision-making.

There are a number of value considerations in developing a care plan, including the patient’s health, long-term agency, well-being, and sources of meaning. Through careful conversation, the patient and the HCP (and surrogate, if needed) could come to learn that the psychiatric disability does cause some pain or obstacle for the patient that should be targeted through medical interventions (whether medication or other therapies). Ideally, the patient and HCP could identify and understand the most vital values and interests at stake. They would be able to trust each other’s expertise in discovering what those values and interests are. For example, the HCP would need to be open to exploring what the patient cares about and finds meaningful. This exploration might be a demanding enterprise, requiring moral imagination and empathic engagement, since the patient’s experiences could be quite removed from those of the HCP. The patient, in turn, would need to be open to discussing the ways in which certain symptoms might be threatening to (e.g.) fundamental dimensions of well-being, such as personal security. If at all possible, the HCP and patient (and perhaps surrogate) would work together to find a care plan that helps the patient recover holistically. Holistic recovery would incorporate a) CR when they agree that certain symptoms should be alleviated and b) PR when they agree on ways to protect the patient’s sense of self and sources of meaning. For shared decision-making to approximate this ideal, the process would need to span across a long, intensive, and empathic relationship that builds trust and epistemic insight over time.460

460 See Matthias 177.
Bridging recovery orientations could be possible, at least in some cases. Other challenges to shared decision-making are still foreseeable, however. Although CR and PR aims are not always mutually exclusive, they can be. For example, if a patient claims to find her hallucinations meaningful, but the HCP has evidence that the hallucinations routinely put the patient in grave danger, then shared decision-making can come to an abrupt halt. Additionally, treatments or therapies that alleviate some symptoms might not be targeted enough to leave other symptoms untouched. For instance, a patient and HCP could come to agree that the creative bursts associated with bipolar disorder are integral to how the patient views herself and finds community. The patient and HCP could also come to agree that certain parts of this disability are harmful and damaging, such as when the patient sinks into a deep depressive state. The HCP might not be able to treat the depressive side of bipolar disorder in a way that protects the patient’s creativity. If achieving personal recovery and clinical recovery are mutually exclusive at any point, the HCP and patient (and surrogate if needed) will need to discuss trade-offs.

Competing values should be weighed in a trade-off discussion. Although a psychiatric disability might be cared about and meaningful to the patient, it can also threaten to push the patient below a decent minimum threshold for well-being. The HCP might have evidence that without treatment, the psychiatric impairment will lead to degeneration of the patient’s agency, making it so the patient’s actions are less purposeful or deliberative. As a result of a psychiatric episode, the patient might desire severe fasting, though this can cause an emergent electrolyte imbalance and medical instability. To the extent that the patient is capable of contributing to this trade-off discussion, the patient should be invited to do so. The patient will be the one who has to live with the costs of whatever decision is made, and the patient’s lived experiences will be
critical for understanding what costs should be permitted. As I detailed in the last chapter, sacrificing what is cared about and meaningful can have devastating effects on a patient’s sense of self. If this substantial sacrifice is going to be part of shared decision-making, then all of the parties to the decision should have some evidence that the benefits for the patient will significantly compensate for the loss. They cannot confidently come to that decision unless they have insight into the patient’s lived experiences. This is not to say that the patient’s subjective viewpoint is ethically determinative; rather, the point is that shared decision-making cannot neglect the experiential knowledge of the patient.

If the patient and HCP are to progress in shared decision-making toward recovery, there are additional missteps that each party will need to avoid. On the patient’s side, she needs to acknowledge any harms associated with the pleroma. If the patient instead becomes defensive or dismissive when those harms are brought up, then the patient’s judgment will not be as informed as it should be for shared decision-making to succeed. The patient’s concerns and values also need to have some internal consistency; if the patient’s professed values contradict or undermine each other, then the patient and HCP will need to resolve them. For HCPs, they need to avoid framing all disabled modes of being as necessarily harmful. For example, if in a particular case HCPs have no concrete evidence that a patient is harmed by hearing voices, then hearing voices should not be framed negatively in discussions with the patient. HCPs have to guard against overly narrow views of what it means to flourish, to have agency, or to have pleroma. HCPs have to avoid conflating what is meaningful with what is laudable, since what the patient finds personally valuable might not fit social norms or moral ideals. HCPs have to be open to
reimagining these most basic concepts, which involves openness to the knowledge claims and recovery aims of patients.

CONCLUSIONS

This chapter delves into an area of critical significance for users/survivors – the therapeutic relationship. This relationship can be a source of interpersonal recognition or misrecognition, depending on whether the patient is invited as genuine participant in decisions of high importance. Shared decision-making, if conceptualized properly and executed well, should avoid consumerism and paternalism. It should empower the patient to the right extent and in the right way, so HCPs’ professional and ethical duties to the patient are respected as well. In mental health contexts, shared decision-making will run into various obstacles. I identified two: insight evaluations and recovery orientations. Although there are good reasons to assess patients’ level of awareness of their psychiatric condition, these assessments can be deeply problematic, and they should not carry too much weight in the overall evaluation of patients’ potential epistemic standing in decision-making. Clinical recovery and personal recovery orientations can lead to irreconcilable differences, but they can potentially be fused through holistic recovery. If HCPs and patients can agree on therapeutic aims consistent with holistic recovery, then shared decision-making has hope of succeeding.

From her own experience, Patricia Deegan writes: “But now that you have been labeled with mental illness the dignity of risk and the right to failure have been taken from you.” [461] The

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[461] Deegan 361
“dignity of risk” is a complicated notion in mental health contexts, since concerns about incapacity, poor insight, and overall poor judgment are ever-present. Working toward shared decision-making is an important step in respecting the patient as an individual and giving space to mental diversity. Shared decision-making, when approached with nuance and care, will empower the patient and mental health professional in striving for holistic recovery. Together, they will have to explore what trade-offs are medically and ethically acceptable, which can be a challenging endeavor when the parties to the decision come from radically different perspectives. I have offered beginning steps forward, so HCPs and patients (and surrogates) can be more open to each other’s’ epistemic insights, expertise, and value contributions.
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