Inclusion Toward Transformation: Psychosocial Disability Advocacy and Global Mental Health

Justin M. Karter

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INCLUSION TOWARD TRANSFORMATION:
PSYCHOSOCIAL DISABILITY ADVOCACY AND GLOBAL MENTAL HEALTH

A Dissertation Presented
by
JUSTIN M. KARTER

Submitted to the Office of Graduate Studies,
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INCLUSION TOWARD TRANSFORMATION:

PSYCHOSOCIAL DISABILITY ADVOCACY AND GLOBAL MENTAL HEALTH

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ABSTRACT

INCLUSION TOWARD TRANSFORMATION:
PSYCHOSOCIAL DISABILITY ADVOCACY AND GLOBAL MENTAL HEALTH

August 2021

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The Movement for Global Mental Health (MGMH) has been met with criticism for reifying Western conceptions of mental disorders and diverting resources from the investigation, intervention, and education regarding the social determinants of mental health. Advocates identifying as a person with a psychosocial disability are organizing to transform the MGMH from a top-down, individualized, and universal approach toward a rights-based conception that accounts for the cultural, political, and economic conditions that produce distress and disability. Using a qualitative, hermeneutic, interpretative-phenomenological analysis (IPA), this research study focused on how people with a lived experience of mental distress and treatment come to question the mainstream discourses of the psy-disciplines, identify as people with psychosocial disabilities, and engage in advocacy both within and against the MGMH. The results contribute to debates on how to conceptualize madness/distress, reveal the emergence of the psychosocial disability identity as a major
force in mental health advocacy. and point to the transformative potential of an integrated psychosocial disability framework for a more rights-based approach. Recommendations are made for mental health researchers, practitioners, and activists to promote and enhance the inclusion of people with lived experience.
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CHAPTER 1
INTRODUCTION

The Movement for Global Mental Health (MGMH) has been met with criticism from cross-cultural and critical psychiatrists and psychologists, as well as psychiatric survivors, service-users/consumers, and people with psychosocial disabilities, for reifying Western conceptions of mental disorders and diverting resources from investigation, intervention and education regarding the social determinants of mental health (Mills, 2014; Beresford, 2018). The writing and activism of people with lived experience of mental distress and treatment within the low- and middle-income countries (LMICs) of the Global South, targeted for the scale-up efforts of the MGMH, present a counter-discourse to that characterized by the psy-complex (Rose, 2018). Activists who identify as persons/people with psychosocial disabilities and use this term to engage in advocacy efforts, herein referred to as psychosocial disability advocates, are organizing to transform the MGMH from a top-down, individualized, and universal approach, toward a rights-based conception that accounts for the cultural, political, and economic conditions that produce distress and disability (Davar, 2008).

Using a qualitative, hermeneutic, interpretative-phenomenological analysis (IPA), this research study focuses on how people with a lived experience of mental distress and treatment have come to question the mainstream discourses of the psy-disciplines, identify as people with psychosocial disabilities, and engage in activism with the MGMH.
The results provide novel insights into how the psychosocial disability framework, as it is lived by those who have adopted it, contributes to debates on how to conceptualize madness/distress. The lived experiences of people with psychosocial disabilities, as described in these results, also shed light on how psychosocial disability has emerged as an umbrella term for mental health advocates with lived experience, altering the landscape of mental health advocacy. In addition, the perspectives of the participants in this study on their engagement with the MGMH speak to how global mental health research and policies would be fundamentally transformed toward a rights-based approach by a thorough integration of the psychosocial disability framework.

The results of this study can also be used to develop strategies for mental health researchers, practitioners, and activists to promote the inclusion of people with lived experience. Additionally, the results may be useful in developing policy recommendations for moving the MGMH toward a rights-based approach.

**Conceptual Framework: Discourse, Subjectivity, and Madness**

A variety of terms have been used to denote what is often referred to in the mental health field as mental disorders, each with their own historical resonances, conceptual baggage, and groups of supporters and detractors (Pilgrim, 2007). Currently, the most common referents for mental distress are the various diagnoses outlined in the Diagnostic and Statistical Manual of Mental Disorder (DSM-5) and the similar International Classification of Diseases (ICD-11). These categories, however, are controversial and often eschewed by those aiming to denaturalize the assumptions that often come with these terms (Karter & Kamens, 2019). The term “madness,” while potentially viewed as anti-scientific or stigmatizing, is often favored by those who resist a reductive medical approach and may refer
to themselves as “psychiatric survivors,” “consumers,” “service-users,” or those with “psychosocial disabilities” (Adame, 2014; Dhar, 2019). While terms such as “mental illness,” “mental disorder,” and “brain disorder” appear more commonly as the object of investigation in the psy-disciplines, “madness” is a term with deeper historical roots that refers to a broader conception of experiences of distress and unreason than that captured through a medical lens.

Following Scull (2015):

Madness has much broader salience for the social order and the cultures we form part of, and has resonance in the world of literature and art and of religious belief, as well as in the scientific domain. And it implies stigma, and stigma has been and continues to be, a lamentable aspect of what it means to be mad. . . The social and the cultural dimensions of mental disorders, so indispensable a part of the story of madness in civilisation over the centuries, are unlikely to melt away, or prove to be nothing more than epiphenomenal features of so universal a feature of human existence. Madness indeed has its meanings, elusive and evanescent as our attempts to capture them have been. It remains a fundamental puzzle, a reproach to reason, inescapably part and parcel of civilisation itself. (p. 14)

Indeed, the term is also resonant with the work of Michel Foucault in *Madness and Civilization* (1967), which sets the conceptual framework for this analysis. Foucault challenges the notion that madness is primarily a property of individual consciousness; he demonstrates this through his archaeological method, which excavates radically different ways of thinking and speaking about madness, referred to as discursive formations, over place and time. In doing so, he reveals a nuanced interplay between individual psyches and social formations, subjectivity, and discourse. Foucault’s archaeological method exposes the historical and cultural contingency of conceptions of madness, as different discursive formations have taken precedent at different times with marked changes occurring through epistemic shifts. In later work such as *Discipline and Punish* (1977/1975), Foucault employed a genealogical method to further add to this analysis, elaborating the ways in
which power over knowledge production is connected to epistemic shifts and differing discursive formations.

Investigations of madness, following Foucault, have observed the rise of the modern mental health fields and the power they wield over current discursive formations. The term “psy-disciplines” (Rose, 1998) has been used to denote all of the disciplines (psychology, psychiatry, psychotherapy) that attempt to conceptualize, describe, and intervene upon the human mind generally, and disorders of the mind, or “madness,” in particular. From a discourse-analytic and Foucauldian perspective, the power of the psy-disciplines to affect global mental health policy goes beyond involvement in the medico-legal details—important as these are—and includes the power to produce forms of subjectivity (Parker, 1997).

Subjectivity, as used here, refers to the modes of life or the possibilities for lived experience that are available within a particular historical and social context (Heyes, 2010). The “psy-complex,” which Rose (1985, 1989) uses to denote the “complex discourses, practices, agents, and techniques” of the psy-disciplines (Rose, 1985, p. 9), thus refers to the multiply interconnected but distinct ways in which the theories and practices of the modern psy-disciples affect contemporary subjectivity: constructing categories into which subjects and societies are placed, practices for observing, measuring, and tracking subjects so categorized, and the living out of particular ways of being produced by these constructs (Parker, 1997, p. 4).

Recognizing the “psy-complex” involves coming to grips with the power of the field not only to define and categorize human experience but also, in some ways, to create it; to “make up” people (Hacking, 1986). Following the sociologist Nikolas Rose (2003), the question that confronts the psy-disciplines is “the question of ethics as Lebensführung: what kind of
creatures do we think we should become?” Indeed, there exists a rich and varied literature representing dissenting voices within the psy-disciplines and the social and human sciences more broadly, as well as those subject to the theories and practices of the field, that critiques the prominent discursive constructions of their time and points to their harms and limitations (Adame & Knudson, 2007; Bracken & Thomas, 2010; Cohen, 2016) along with the boundaries and obstacles that limit the diversity of voices included in the broader discourse (Jones & Brown, 2012). Thus, the ethical question confronting the psy-disciplines is not just one of discourse (how to speak of madness), but one of politics and participation (whose accounts “matter”). In this way, contemporary critical engagement with the psy-complex seeks to go beyond Foucault’s work to incorporate an analysis of power with greater attunement to the histories and ongoing legacies of racism and colonialism (Weheliye, 2014).

Efforts to disrupt the epistemic power of the psy-disciplines through diversifying inclusion and participation are undertaken in different forms within different spheres of praxis, ranging from individual interactions to research methods to local and international policy, among others. For example, in individual clinical interactions, critical psychiatrists have called for a privileging of accounts and descriptions by service users and patients of their distress to avoid imposing the diagnostic and explanatory models produced by the field (Bracken, 2014). In the research context, qualitative methods such as phenomenology and hermeneutics prioritize the lived experiences of participants, rather than attempting to fit their experiences into pre-determined constructs as in positivist research. In this way, qualitative research allows participants’ first-hand descriptions of mental distress, formulated in their own terms, to enter the body of knowledge attached to the psy-disciplines. At a structural level, people with lived experience, critical researchers and practitioners work to
remove barriers to full equality and participation in society by way of community
gagement, connectedness, and integration (Bromage et al., 2019). For example, in the
effort toward deinstitutionalization, the movement for democratic psychiatry (McLaughlin,
2003) found it necessary to challenge medical and legal practices preventing full citizenship
at the same time that it worked to challenge cultural stereotypes about madness (Schepers-
Hughes & Lovell, 1986). Recent work in critical disability studies extends this tradition,
arguing that social and structural change is necessary for inclusion and that full inclusion
necessitates a transformation of normative standards (Dirth & Adams, 2019). Toward this
end, organizations such as the National User Survivor Network (NSUN) campaign for full
legal equality for people labeled mad, and call for protection from coercive practices within
the psy-disciplines such as forced treatment, as well as from discriminatory practices in
employment and other social institutions (Sayce, 2017). Additionally, organizations run by
people with psychosocial disabilities have emerged, primarily in the Global South, aiming for
the full and effective inclusion of people with lived experience in research and policy efforts
as well as society at large. For example, the Bali declaration by TCI Asia-Pacific, the Cape
Town declaration by the Pan-African Network of Persons with Psychosocial Disabilities, and
the Lima declaration by the Redesfera Latinoamericana de la Diversidad Psicosocial all
contest the continued efforts of the psy-disciplines to exclude the voices of people who are
the “objects” of theorizing and treatments (TCI Asia-Pacific, 2018; PANUSP, 2011;
Redesfera, 2018).

These efforts toward epistemological and ontological diversity remain largely marginal
to the hegemonic theories and practices of the psy-disciplines, however (Hoffman, 2016).
Such continued marginalization is perhaps most evident in the Movement for Global Mental
Health (MGMH) (Davar, 2016; Fernando, 2017; Klein & Mills, 2017), which aims to uncritically scale up the dominant concepts and practices of the psy-disciplines internationally. Especially in light of this development, an approach to global mental health is needed that would be capable of appreciating the cross-cultural variation in mental and emotional life as well as the socio-political influences on madness and well-being. In this sense, the psychiatric survivor, service-user, and psychosocial disability rights movements may constitute unique “counter discourses” to those promoted by the MGMH, albeit with less institutionalized power (Foucault, 1980).

**Purpose of Study**

This study aims to investigate such a counter or alternative discourse through the experiences of individuals who experienced madness/mental distress, been subjected to the discourses and practices of the psy-disciplines, identify as people with psychosocial disabilities, and are currently engaged in various forms of activism related to the MGMH. There is a gap in the current literature when it comes to the experiences of psychosocial disability advocates in the context of the MGMH. This study will add to the existing literature by specifically addressing how people with psychosocial disabilities navigate their identity and mental health activism while confronting and seeking to reform the MGMH. Using a qualitative, hermeneutic, interpretative-phenomenological approach (IPA), this research will focus on how people with a lived experience of mental distress and treatment came to identify as a person with a psychosocial disability and engage in advocacy around the MGMH. The results of this study can be used to develop strategies for mental health researchers, practitioners, and activists for a more systematic inclusion of people with lived
experience. Additionally, the results may be useful in developing policy recommendations for moving the MGMH toward a rights-based approach.

**Research Questions**

The study was driven by the following research questions:

1) How did the participants’ lived experience of mental distress and treatment shape their identity as people with psychosocial disabilities engaged in advocacy?

2) How does the psychosocial disability framework shift how advocates make meaning of their activism in the context of the Movement for Global Mental Health (MGMH)?

3) What are the advantages of using a psychosocial disability framework when engaging in advocacy related to the Movement for Global Mental Health (MGMH) and what barriers do these advocates face?
CHAPTER 2
LITERATURE REVIEW

The field of mental health research and practice faces sustained critique on many fronts. Critics of the psy-disciplines from within psychiatry, psychology, and the social sciences, as well as those with personal experience with mental health treatment, have taken the field to task for a myriad of issues, including: the corruption of research, practice guidelines, and treatment (Cosgrove et al., 2018); the undue influence of the pharmaceutical industry (Whitaker & Cosgrove, 2015); the lack of validity of prominent diagnostic constructs (Phillips et al., 2012; Karter & Kamens, 2019); over-diagnosis, over-treatment with psychopharmaceuticals, and medicalization (Moncreiff & Crawford, 2001; Frances, 2010); the pathologization and disempowerment of those engaging with mental health services (Hornstein, 2017); and complicity with (and reproduction of) oppressive and marginalizing social systems and ideologies (Parker, 2009; Metzl, 2010; Cosgrove & Karter, 2018), including colonialism, among others.

Cutting across each of these debates are issues surrounding the cross-cultural relevance and application of the Western psy-disciplines and its attendant discourses, technologies, and products. Broadly, these can be divided into two discussions: those seeking to improve access to the standard mental health treatments available in the Global North for those in marginalized or underserved populations, both domestically and internationally, and those investigating the social determinants and “global burden of obstacles” to mental health and well-being (Pūras, 2017), including the misapplication of the psy-disciplines as a potential
obstacle (Whitley, 2015). The following brief history of some major debates in cross-cultural and transcultural psychiatry aims to place the current disagreements over global mental health in sufficient context. Meanwhile, an analysis of these arguments over time illuminates the political and ideological stakes at play, opening a space for reflecting on contemporary debates over culture and madness.

**Finding Ourselves: Madness and Culture**

Arguments about the role of culture in psychiatry are as old as the discipline itself (Jilek, 1995). When psychiatrists in the colonial period began to set up mental asylums and study mental disorders among the indigenous populations of India and the Americas, they initially concluded that these populations suffered from few such issues (Chakraborty, 1991). One simple line of thinking used to explain this observation was that mental disorders likely arose as a product of Western civilization; that the demands of high culture produced mental stress and the working conditions of the poor in urban settings eroded health (Raimundo Oda et al., 2005). According to this line of thought, natives, seen as “healthy primitives,” were not “mad” because they did not suffer the deleterious effects of civilization (Kirmayer, 2007). However, when accounts of what was termed “native madness” began to be reported by psychiatrists working in colonial hospitals, these narratives challenged earlier assumptions about the role of culture in mental disorder in a way that threatened to undermine larger political narratives about the beneficent and civilizing effects of colonialism. If natives were capable of madness, this could mean that they were just as “intellectually advanced” as their colonizers. Alternatively, psychiatrists of the time may have asked themselves whether these newfound cases of madness were somehow a result of something new in the lives of the
native populations, perhaps even the presence of the colonizers themselves (Littlewood & Bhugra, 2001).

By the mid-19th century, a solution to this ideological cognitive dissonance arose. A new British-German biological approach to madness and mental disorders posited that psychiatric problems were universal conditions arising from pathological biological processes internal to the person, and only mediated in their expression by culture and language, thus producing “culture bound syndromes” (Yap, 1974). This biomedical approach is often traced to the work of Emil Kraepelin, considered the father of modern psychiatry. In 1904, Kraepelin studied “major psychoses” in Southeast Asia and Indonesia, concluding that these disorders were universal and that any differences in phenomenology may be explained by differences in intellectual development. The comparatively low rates of delusions among the Javanese were hypothesized as “related to the lower stage of intellectual development attained…” or “might reflect the fact that speech counts for far less than it does with us and that thoughts tend to be governed more by sensory images” (Kraepelin, 1904, as cited in Kirmayer, 2018). In 1923, the German-American psychiatrist Karl Birnbaum famously made the distinction between pathogenesis and pathoplasticity in psychiatry, with pathogenic factors referring to the underlying biological structure of the mental disorder and pathoplastic factors referring to how these universal structures may be translated differently by culture (Birnbaum, 1923 as cited in Murphy, 2011).

Although this approach is often understood as a scientific advance in traditional histories of the field, it is also evident that shifting to a biological explanation of mental disorders may have obscured the relationship between colonialism and the madness of native populations. For instance, within Birnbaum’s conceptualization, the question might have been asked, "Did
colonization do anything more than re-label local deviances; can we say that in itself it was pathogenic in any empirical sense?” (Littlewood & Bhugra, 2001, p. 14). Historical work on the accounts of British and French psychiatrists in this period support this point, as their writings present “accounts of dysfunction that they localized in ‘the indigenous mind,’ and almost never in a culture of political and racial oppression” (Keller, 2001, p. 297).

The writings of Kraepelin and colonial psychiatrists echo throughout current debates over the cross-cultural applicability of psychiatric diagnostic constructs. The Diagnostic and Statistical Manual of Mental Disorders (DSM), which was explicitly developed based upon the universalist ideas of Kraepelin (Compton & Guze, 1995), has historically used the concept of “culture-bound syndromes” to assist practitioners in recognizing divergences from “standard,” i.e. Western, patients. Similarly, the etic-emic distinction in philosophy of science marks a divide between traits that apply to all humans—for example, the necessity of eating and drinking, referred to as “etic” (from phonetic, meaning language general)—and traits that are unique to a particular context, referred to as “emic” (from phonemic, meaning language-specific), like certain religious practices (Pedersen, 1999). In the most recent edition of the manual, DSM-5, the concept of “culture-bound syndromes” was replaced with “cultural syndromes,” “cultural idioms of distress,” and “cultural explanation/perceived distress” (APA, 2013). While this new formulation broadens the understanding of culture to include descriptions of experiences made available by particular cultural contexts and not just mediated by them, it fails to recognize that the most common DSM diagnoses may themselves be products of the particular cultural and material conditions of the contemporary Western societies in which they were developed (Phillips, 2013; Ecks, 2016; Bartholomew, 2000).
There has been a steady resistance to these neo-Kraepelinian theories characteristic of Western psychiatrists and psychologists, from researchers and activists pushing for a recognition of the role that colonial contexts and oppressive practices play in the creation of mental and emotional distress (Littlewood, 1990). In Peau noire, masques blancs (Black skin, white masks; 1952), Fanon dismissed the assumptions of Western psychiatry as racist, arguing that colonialism was responsible for producing a form of psychopathology and that oppressive practices become inscribed psychologically on the colonized.

Beginning in the 1960s, the antipsychiatry movement in the United States, led in large part by former patients identifying as psychiatric survivors, joined forces with anti-war and antiauthoritarian movements to challenge the use of psychological constructs for social control (Boyers, 1974). In 1977, Arthur Kleinman introduced an approach termed the “new cross-cultural psychiatry,” which challenged the universality of mental disorders and made use of anthropological and ethnographic methods to study the meaning of particular forms of distress within their social, historical, and cultural contexts (Kleinman, 1977, 1986, 1997). Within the “third phase in the history of cultural psychiatry” (Kirmayer, 2007), where the mental health fields are approached anthropologically, critical psychiatrists point to the role of the pharmaceutical industry in the production of mental health constructs and treatments (Moncrieff et al., 2005; Whitaker & Cosgrove, 2015; Steingard, 2019). At the same time, critical psychologists have attended to role of psychological concepts within larger social and political systems (Parker, 2015; Hook et al., 2004; Teo, 2014; Cohen, 2017). Despite the prominence of Kleinman’s approach, and the resultant body of knowledge on culturally located forms of distress, mainstream psychology and psychiatry has largely ignored the investigation of how mental health practices and institutions themselves contribute to the
emergence of certain experiences of mental and emotional suffering (see e.g., Rose & Abi-Rached, 2013; Watters, 2010).

This brief overview has aimed to illustrate two major points: (1) different approaches to understanding madness and mental disorder throughout time have reflected the ideological and political interests of those in the West; and (2) there remains substantial cause for concern when Western mental health diagnoses and treatments are used in non-Western populations. Unfortunately, mainstream psychiatry and the psy-disciplines have failed to heed the concerns raised throughout this history, instead continuing to approach madness from a decontextualized point of view that not only privileges Western frameworks, but also reifies and centers these concepts as the universal standard against which all others are measured. Indeed, at a time when substantial challenges have been posed to the underlying assumptions of the field as well as its predominant treatment strategies, and while globalization and mass migration makes it clear that no heterogeneous population exists in which these categories can be reliably applied, mainstream psychiatry is doubling down on efforts to ply its trade the world over without serious engagement with questions of culture and power (Fernando, 2012; Summerfield, 2013).

**Doubling Down and Scaling Up: The Movement for Global Mental Health**

Most recently, these debates have centered on the Movement for Global Mental Health (MGMH), launched in 2007 by a group of experts known as the Lancet Group for Global Mental Health (Patel et al., 2007; 2011, Chisholm et al., 2016). Advocates of the MGMH call to “scale up the coverage of services for mental disorders in all countries, but especially in low-income and middle-income countries” (Chisholm et al., 2007, p. 1241) and to “close the treatment gap” between those who need treatment and the small number who receive it
(Chisholm et al., 2011, p. 1242). The World Health Organization (WHO) issued the Mental Health Gap Action Programme (mhGAP) guidelines in 2010, framing mental health as a priority for global development (World Health Organization, 2010).

Further, in 2015, mental health was included in the United Nations (UN) sustainable development goals (SDGs) with the intention of incentivizing programs that address mental health care within international development plans (United Nations, 2015). Additionally, the World Bank and the International Monetary Fund (IMF) have advocated for addressing mental disorders globally as a means of increasing economic productivity (Mnookin, 2016).

The Lancet Psychiatry formed a Commission on Global Mental Health in 2016, with the goal of developing research and intervention implementation plans for the MGMH (Patel et al., 2016). On October 10, 2018, World Mental Health Day, the Lancet Commission published a report outlining a framework and proposal for “scaling up” mental health care globally (Patel et al., 2018). In concert with this release, the UK government hosted a Global Mental Health Ministerial Summit with the intention of laying out a course of action to implement mental health policies globally.

The MGMH contains a diversity of viewpoints on culture and mental health, with some acknowledgment of the need to adapt methods and interventions to specific contexts. The thrust of this movement, however, assumes that the current conceptual, diagnostic, and treatment approaches of psychiatry can be applied without engaging ethnographic and anthropological work and without critical reflexive analysis of the evidence-base of the Western mental health field (Beresford, 2018; Kirmayer & Pedersen, 2014). Across the reports and publications produced by different players in the MGMH, including academic groups and large international development organizations, the framing of mental distress
ranges from categories such from “mental health problems,” “mental illness” and “mental disorders” (De Silva & Roland, 2014), to “behavioral, developmental and neurological disorders” (United Nations, 2015). As Mills (2018) argues, these reports locate distress primarily within the brain and presents mental disorders as “highly prevalent, accounting for a large burden of disease” (p. 849).

Claims concerning the prevalence and burdensomeness of mental distress have their roots in epidemiological data attempting to utilize the measures and metrics of physical illnesses for the calculation of statistics related to mental disorders (Bemme & D’souza, 2014). Starting in 1991, the World Bank and the WHO initiated the Global Burden of Disease studies (GBDs) in an attempt to quantify the role of medical interventions in economic development and to assess progress toward them (Murray & Lopez, 1996). One of the indicators utilized by the GBDs to compare different disease categories is the Disability-adjusted Life Year (DALY) metric, which calculates how many years of life are lost to a disease category due to early death or loss of functional abilities from disability. The 2010 GBD study included “mental, neurological, and substance use disorders,” and a key finding was the rapid increase in non-communicable diseases in low- and middle-income countries (LMICs), with the proportion of the burden attributable to these diseases rising from 36% in 1990 to 49% in 2010 (Murray et al., 2012; Charlson et al., 2014). As alluded to earlier, these statistics assume (and reproduce the assumption) that categories of mental distress, such as depression, anxiety, schizophrenia, etc., apply universally across different cultures and locales.

Similarly, in a study for the World Economic Forum, Bloom et al. (2011) attempted to calculate the economic cost of mental disorders, finding that the global cost of these
disorders would reach US$6 trillion by the year 2030 accounting for a large percentage of all lost output and productivity worldwide. Going further, a 2016 study estimated that without the implementation of treatments worldwide, depression and anxiety disorders would cost the 36 largest companies in the world US$925 billion every year (Chisholm et al., 2016, p. 419). This suggestion of course assumes that it is possible to increase life expectancies through “health interventions alone, rather than non-health sector (developmental) interventions” (Das & Rao, 2012, p. 384; see also Anand & Hanson, 2004).

The most recent reports released by the WHO (2017) suggest that anxiety and depression impact 260 million and 322 million people around the globe, respectively, with 3.6% of the global population living with an anxiety disorder and 4.4% living with depression. While the prevalence of common mental disorders appears to be increasing most rapidly in the LMICs of the Global South, with almost “half the number of people living with depression residing in South-East Asia and Western Pacific regions,” the report suggests that the increase in anxiety disorders was particularly high in the Americas, with the prevalence increasing by 18.4% between 2005 and 2015 (Friedrich, 2017, p. 1517).

There are a number of assumptions made in these calculations, some of which will be addressed below, but the foundational issue remains whether or not mental distress across the globe can be adequately captured by Western diagnostic constructs (Brhlikova et al., 2011). The MGMH makes a case for the urgent implementation of standard mental health interventions based on these dire statistics; yet such measurements rest on the problematic assertion, one that has been called into question throughout the history of cross-cultural psychiatry, that culturally specific and complex experiences of distress can be reduced to illness definitions which are alien in many contexts (Fernando, 2014; Summerfield, 2008).
The assumption that LMICs in the Global South do not have culturally specific ways of responding to mental distress—with the implication that quantitative metrics like the ones above are to be taken literally—contributes to this sense of urgency in the MGMH, leading to the development of simplified and resource-poor interventions that are increasingly technical rather than holistic (Bemme & Kirmayer, 2020).

**Counter-Narratives Against Global Mental Health**

Although the MGMH has continued to pick up steam, gaining funding and the support of international organizations (Rose, 2006; 2018), it has also been met with considerable resistance from critical scholars and mental health activists with lived experience (Beresford, 2018; TCI Asia-Pacific, 2018; PANUSP, 2011; Redesfera, 2018). Previous research suggests that the MGMH primarily reproduces a discourse that reifies Western conceptions of mental distress (Mills, 2014).

In 2012, the National Institute of Mental Health (NIMH) announced an initiative, “Grand Challenges to Global Mental Health” (Collins et al., 2011). The initiative was outlined in an article in *Nature* accompanied by an image of an African child chained to a tree, ostensibly to demonstrate the human rights abuses that might occur in the Global South if mental health treatments, developed in the Global North, were not implemented there (Mills, 2014). Critics and service-user activists responded with a letter making six key critiques (Shukla et al., 2012). A discussion of each of these six points (as summarized by Mills, 2014, p. 4-5) is useful for presenting the major arguments that have been made against the MGMH.

**Lack of Collaboration with Local Communities and Survivors/Service-Users**

Survivors and users of psychiatry and mental health care more generally, and those who self-identify as people with psychosocial disabilities, represent a heterogeneous group who
have made a wide range of critiques of the MGMH (a point which will be elaborated later). However, several points are made consistently across these groups: an assertion of a right to define their own distress and to choose the type of healing spaces they find most useful, and a call for the inclusion of “experts by experience” in all phases of the MGMH (Mills & Fernando, 2014).

The lack of inclusion of service-user, survivor, and psychosocial disability groups has been a recurring issue throughout the development of the MGMH. In 2011, the Pan-African Network of Persons with Psychosocial Disabilities (PANUSP)—formerly the Pan African Network of Users and Survivors of Psychiatry—produced the Cape Town Declaration, which declared, “There can be no mental health without our expertise. We are the knowers and yet we remain the untapped resource in mental health care. We are the experts. We want to be listened to and to fully participate in our life decisions” (PANUSP, 2011). In response to the “Grand Challenges to Global Mental Health” project, Shukla et al. (2012) reiterate this message: “Developing appropriate frameworks for mental health requires active collaboration with local communities and with those who have personal experience of mental health problems.” Yet, “The Delphi panel was not representative of these stakeholders” (p. 4). The lack of inclusion in the Grand Challenges to Global Mental Health report was then exacerbated by Nature’s refusal to print the critical letter, providing further evidence of the unwillingness of the psy-disciplines to hear the voices and concerns of people with lived experience.

**Evidence Exaggerates Prevalence**

The critical response to the Grand Challenges report in Nature suggests that the epidemiological data used by the MGMH “is also questionable and could grossly exaggerate
the global burden of mental disorders” (Shukla et al., 2012, p. 4). Indeed, critics have suggested that prevalence figures, such as those concluding that depression is the leading cause of disability worldwide (Friedrich, 2017), “insult our common sense and everyday experience” (Summerfield, 2012, p. 520). The estimates of the MGMH are based on the assumption that psychiatric constructs, developed by Western psy-disciplines and most often developed and tested on Western, Educated, Industrialized, Rich and Democratic (WEIRD) samples, can adequately capture the experiences of “madness” or mental distress in diverse cultural settings (Schulz et al., 2018). As Summerfield (2017) writes, using instruments that assume a “mental disorder’ is an entity essentially lying outside situation, society and culture, which is identifiable anywhere using a common (Western) methodology,” “cannot be redeemed by reliability–using a standard reproducible method–since the very ground they stand on is unsound” (Summerfield, 2017, p. 52).

Even when assuming the cross-cultural appropriateness of using Western diagnostic constructs in non-Western settings, epidemiological analyses have criticized the GBD studies for the value judgments inherent in DALY metrics, the low quality of data in LMICs without robust health surveillance systems, and the uncritical use of the GBD estimates in academic studies and policies (Brhlikova et al., 2011). In the case of depression estimates, the GBD data were generated using a wide range of different measures and scales, which often did not allow for the use of clinical judgement in screening or diagnosis. Some screening instruments may vary significantly in the likelihood of identifying depression (Levis et al., 2018), the seven common depression rating scales share only 12% of the symptoms across all instruments (Fried, 2016), and many scales are inconsistent with DSM-5 diagnostic criteria for major depressive disorder (MDD) (Fried, 2017). The use of structured vs. semi-structured...
instruments may also substantially affect depression estimates: “In general population samples, where depressive symptom levels are generally low, major depression prevalence has been found to be substantially higher when fully structured interviews are used versus semi-structured interviews” (Levis et al., 2018, p. 6). The most common depression measures used in the GBD study, the Diagnostic Interview Schedule (DIS) and the Composite Diagnostic Interview Schedule (CIDI), are highly standardized and structured interviews, often conducted by laypeople (Brhlikova et al., 2011). Almost the entirety of validation studies for the CIDI were completed in Western samples, and its cross-cultural reliability and validity have been challenged (Ferrari et al., 2013). Moreover, GBD data from LMICs in South-East Asia and Africa was often not based on nationally representative samples and was extrapolated from studies from a small area, or even a single village (Brhlikova et al., 2011).

The individualistic focus of the MGMH is evident in the lack of attention to forms of community distress, which is different from the sum of the distress of individual members (Fernando, 2012). A perspective on global mental health that took social and collective distress as its object, rather than individual pathology, might differentiate thriving communities from distressed communities and identify structural and environmental risk factors for collective distress that are amenable to political intervention rather than individualized treatment (Campbell & Burgess, 2012).

A Focus on the Brain Obscures Context and Lived Experience

The MGMH framing of mental disorders as having a “physical basis in the brain,” and “truly universal” (Sayers, 2001, p. 1085, as cited in Mills, 2018), has been opposed and contested by critical psychiatrists and psychologists, transcultural psychiatrists, and those with lived experience of psychiatric treatment (Mills & Fernando, 2014). Critics contend
that the framing of mental distress as illness or brain disorders obscures the cultural differences in mental and emotional life and obscures the social determinants of mental health.

The social determinants of mental health are the social, economic, and material factors that affect the mental health of communities (Raven, 2013). A 2014 analysis by the WHO concluded that political, social, environmental, and economic situations have powerful effects on mental well-being. Discrimination, poverty, unemployment, low educational opportunity, lack of social support, and lack of trust in others are all linked to higher levels of psychological distress (WHO, 2014). The cultural and social contexts of a community shape the ways in which people respond to - and make meaning of - their material conditions.

Summerfield (2008) refers to the difficulty of measuring “mental health in a broken social world” where “structural poverty and injustice, violent conflict, debt repayments, shifting weather patterns, environmental degradation, and inadequate budgets for health, education, and social welfare provide a barely viable social context for millions of people” (p. 993). He points to research suggesting that the mental health of refugees is strongly moderated by social conditions after displacement and the resolution of the conflict, suggesting that the “mental phenomena being identified as satisfying criteria for a mental disorder (typically depression or post-traumatic stress disorder) were mostly incidental and a normal reaction to their circumstances” (p. 993).

Prevalence estimates in the GBD study reveal that anxiety disorders are significantly higher in populations exposed to conflict compared to non-conflict populations (Baxter et al., 2013). However, the WHO survey found that anxiety disorders were most common in non-conflict countries like the United States (10.1%). This discrepancy in the findings has been
attributed to the WHO’s “use of nationally representative sampling frames in contrast to other studies where single regions (possibly one known to have been exposed to direct conflict) were selected” (Baxter et al., 2013, p. 11).

Pointing to the influence of relative inequality on mental health, the WHO report quotes Amartya Sen’s insight that, “Relative deprivation in the space of incomes can yield absolute deprivation in the space of capabilities” (Sen, 1992, as quoted in WHO, 2014, p. 35). Indeed, research has found that as the level of living standards decline, the level of psychological distress increases (Foulds et al., 2014) and that levels of income inequality are predictive of the prevalence of a range of mental health conditions—from depression to schizophrenia (Pickett et al., 2006; Burns et al., 2014). This insight makes clear that risk factors for mental distress must also be understood within context, as comparisons of absolute economic assets and mental health would miss the influence of relative inequality within a community, and the social and political dynamics that inform how inequality is encountered and understood.

For example, in 2010, population-level data revealed that India accounted for one-fifth of suicides globally, and that suicide rates in India were much higher in rural areas than urban areas (Patel et al., 2012). Ethnographic and qualitative studies of this phenomenon pointed to the role played by public policies and an “agrarian crisis” in the rise in farmer suicides in rural India (Deshpande & Arora, 2010). However, the population data appeared to belie this explanation, as agricultural workers did not appear to be at a higher risk for suicide than professionals, laborers, and non-workers. As Kennedy and King (2014) point out, the quantitative analysis failed to account for the fact that the occupational categories did not accurately capture the work lives of rural Indians, as it is common for struggling farmers to engage in wage-labor. Indeed, after a reanalysis of the data, it was farmers in a very
particular socio-economic situation—with high debt loads, cash crops, and marginal holdings—who were at a heightened risk for suicide, as suggested in the qualitative studies (Kennedy & King, 2014). Additionally, the introduction of genetically modified crops by large transnational corporations has worsened these issues, leaving farmers with more debt and making them more vulnerable to risks from non-sustainable farming practices (Shiva et al., 1998). This example suggests that large quantitative studies can easily miss the contextual dynamics driving mental health issues; in the case of Indian farmers, depression and suicide might be said to have more to do with socio-economic circumstances and the chemicals in the soil than the chemicals in the brain.

*Indigenous Healing Practices Were Not Considered*

Shukla et al. (2012) argue not only that socio-political issues are individualized and pathologized by diagnosis, but that the discourse of the MGMH may adversely alter local practices. The uncritical application of narrowly biological approaches to mental health may prevent the application of resources to projects aimed at social transformation and local, culturally informed forms of healing (Davar & Lohokare, 2009).

Critics have also attacked the MGMH for reproducing colonial power structures, by defining and implementing mental health in a top-down manner from the Global North (or high income countries; HICs) to the Global South (or low and middle income countries; LMICs). In doing so, MGMH ignores local understandings and forms of distress while failing to consider, and thus marginalizing, traditional healing practices (Davar, 2014).

Moreover, the standard for what constitutes acceptable forms of evidence—namely randomized controlled trials—effectively prevents cultural groups with alternative ways of knowing and/or lacking the means to conduct these studies from contributing alongside the
Western psychiatric evidence base used to inform the MGMH (Summerfield, 2004). In the effort to educate non-Western populations about evidence-based mental health concepts and treatments, Summerfield sees an urge toward “medical imperialism, similar to the marginalisation of indigenous knowledge systems in the colonial era” (2008, p. 993).

It is striking how often published studies of non-Western populations refer to subjects’ “limited knowledge of mental disorders”, their lack of “mental health literacy”, or the need to “teach” health workers and the people they serve about mental health. Thus, non-Western subjects are meant to understand “us”, rather than the other way round, and their own cultural frameworks are likely to be seen as an obstacle to this understanding (Summerfield, 2012, p. 525).

The globalization of mental health discourses from high-income countries is rapidly eclipsing local healing traditions, as well as indigenous ways of expressing and experiencing emotional distress (Gone, 2016). Current attempts to promote mental health literacy through the MGMH do not sufficiently engage with local or folk understandings of the mind and mental distress (Kirmayer & Pederson, 2014). One perhaps paradigmatic example is captured by the anthropological observation that the psychiatric construct of somatization, the tendency to express psychological conflicts in physiological terms, is incompatible with Japanese cultural understandings of the interconnectedness of body and mind (Kirmayer, 1989).

**Funding For Programs Should Not Come From Pharma**

There are a number of vested interests that shape research on the nature of mental health issues and the treatments and interventions designed to address them (Whitaker & Cosgrove, 2015). The interests of the pharmaceutical industry, in particular, have shaped the knowledge and practices of the psy-disciplines and consequently, the MGMH, in both subtle and explicit ways (Kirmayer & Raikhel, 2009). Pharmaceutical companies have had a direct and corrupting influence on the research base of psychiatry by inflating reports of medication effectiveness and downplaying adverse effects through academic-industry partnerships,
ghostwriting, perverse incentive structures, and the manipulation of regulatory authority through institutional corruption (Healy, 2004; Cosgrove et al., 2018). The MGMH is currently engaging in clinical trials across the globe to evaluate the effectiveness and safety of different psychiatric and psychosocial interventions in different communities and cultures. This research has the potential to significantly expand the markets of the pharmaceutical industry, and this incentive in turn has the potential to lead to a substantial corruption of the evidence if appropriate steps are not taken (Roberts, 2020).

Little attention has been paid to the forces that brought about the global mental health framework and its connection to the World Bank and pharmaceutical industry. However, as Bemme and D’ souza (2014) note, the infrastructure for the MGMH was deliberate and orchestrated. Starting in the 1980s when the World Bank began investing in population health as an economic investment, “the WHO subsequently saw itself increasingly side-lined by the World Bank’s funding power and programmatic direction,” and shifted direction toward “Global Health,” moving away from “social projects” toward “global health interventions as projects conceptualizing health in biological and economic terms” (p. 853).

Industry also exerts an undue influence more broadly through the marketing of pharmaceutical products, disease mongering, and the psychiatrization of everyday life (Mills, 2014; Rose, 2016). As a result, the discursive frameworks produced by the psy-disciplines often unwittingly aid and abet neoliberal agendas that make individuals solely responsible for their distress (Esposito & Perez, 2014). The subtle impacts of industry practices on daily life around the globe work in tandem with other global economic and political trends toward privatization and neoliberalism (Cosgrove & Karter, 2018). By describing health within a biological and economic framework, the MGMH is consistent with the neoliberal aim of
bringing social life under the evaluation of the market (Moncrieff, 2008), encouraging individuals to see themselves as “neurochemical selves,” and thinking of “their moods and their ills in terms of the functioning of their brain chemicals” (Rose 2003, p. 28).

**Uncritical Assumption that Human Rights Violations are More Common in the Global South and the West Must Intervene**

Shukla et al. (2012) took issue with “the picture of a black girl chained to a tree on the front of the article in Nature” which “suggests that rights violations are a more prevalent issue in non-Western countries.” They add, “Mental health service delivery has involved rights violations across the globe (e.g., use of seclusion, restraint, high dose medication)” (p. 4). This criticism echoes the attention to the top-down power dynamics of the MGMH where Western knowledge is valued as superior, reminiscent of “the White man’s burden” approach to aid whereby Western experts “can solve world poverty by bringing their superior technical knowledge to the locals” (Easterly, 2006, p. 2060).

A recent WHO investigation of the conditions of adults with psychosocial and intellectual disabilities in Europe found that only one in four psychiatric institutions, out of 75 facilities across 24 countries, met international standards for human rights (WHO, 2018). The standards were based on the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the “first comprehensive and legally binding international framework for psychosocial disability” (Drew et al., 2011, p. 2). The WHO investigation found a general lack of appreciation for mental health and human rights among staff, the lack of humane and personalized treatment plans, the lack of plans for improvement or recovery, and the lack of access to simple activities like reading, calling loved ones, or watching TV (WHO, 2018). In addition, the report describes egregious incidents of gross neglect,
isolation, and sexual abuse (WHO, 2018). The results of this report, combined with the evidence that “human rights violations against people with psychosocial disabilities occur in all countries irrespective of income level.” (Drew et al., 2011, p. 1) may beg the question: “Has psychiatry been such a success here [in HIC’s] to entitle us to export it all over the world?” (Mills, 2014, p. 3).

**Mental Health Activists with Lived Experience**

So far, we have referred broadly to people with lived experiences as service-users/consumers, psychiatric survivors, and people with psychosocial disabilities or the psychosocially disabled. The involvement of these groups in activist movements in the field of mental health is often referred to collectively as consumer, survivor, or ex-patient (C/S/X) perspectives (Schrader et al., 2013). The majority of C/S/X advocacy and scholarship has developed out of the Global North in response to the forms the psy-disciplines have taken within a Western context. Meanwhile, psychosocial disability has largely emerged as an identity within the Global South up to this point. While these identities are sometimes invoked interchangeably, and group membership is often overlapping and collaborative, they entail somewhat different philosophies and positions within the field of mental health activism. An overview of these differing C/S/X perspectives and identities can shed light on how psychosocial disability might extend and/or break with the other movements.

The designation “psychiatric survivor” is an identity taken up by those who “have experienced abuse and/or oppression in the mental health system, and thus have survived psychiatry itself rather than a diagnosis of mental illness per se” (Adame, 2014, p. 457). Psychiatric survivors trace their grassroots activism to the antipsychiatry movement of the 1970s (Hornstein, 2009) and aim for liberation from the psychiatric system and medical
model of mental illness, rather than empowerment within it (Chamberlin, 1978). For this reason, psychiatric survivors organize groups positioned outside of the psychiatric system, including MindFreedom (e.g., www.mindfreedom.org), the National Association for Rights Protection and Advocacy, the National Empowerment Center, and Vermont Psychiatric Survivors, to name a few. These survivor groups have developed alternatives to the mainstream mental health system like peer-run support groups, respite homes for people in distress, and medication-free facilities, while protesting and taking legal action against coercive practices such as forced medicating, solitary confinement, and commitment (Chamberlin, 2004). However, some psychiatric survivors have entered the field of psychotherapy “to be the kind of therapist they would have wanted in periods of acute distress” and “to further the aim of the survivor movement through supporting the creation of alternatives, ongoing activist efforts to protest psychiatric human rights violations, and practicing a broadly humanistic (and existential) approach to working with clients” (Adame, 2014, p. 458).

Psychiatric survivors are differentiated from mental health service-user and consumer groups, “who are more oriented toward psychiatric reform and have also sometimes experienced psychiatric services as helpful” (Hölling, 2001, p. 103, as quoted in Adame, 2014). Survivor groups have taken issue with the tendency of user/consumer advocates to work on reforms to the mental health system from within by taking paid positions as peer-support workers. The recovery movement, which takes a strength-based approach to mental health treatment, has pushed for an incorporation of service-users into the mental health system (Davidson, 2005; Davidson et al., 2012), adding the designations “peer worker” or “peer specialist.” However, some survivor groups have contested the framing of the recovery
movement, and the implication that there is something wrong that needs to be recovered from (Harper & Speed, 2014). Nevertheless, survivors and users do collaborate toward similar aims through organizations such as the World Network of Users and Survivors of Psychiatry (WNUSN).

Psychosocial disability organizations emerging in the Global South have self-consciously positioned themselves within the disability movement, rather than as survivors or opponents of the Western psy-disciplines (Davar, 2008). The disability framework straddles the contested territory between survivors and user/consumers groups by approaching mental distress as disabling only in the context of a failed socio-political response to suffering. In this respect, psychosocial disabilities are not individual medical illnesses but experiences that become disabling as a result of inadequate social supports (Carroll et al., 2016). The psychosocial disability framework promotes the principle of inclusion, calling for the participation of people with psychosocial disabilities in all phases of mental health research and practice, similar to user/consumers and peers within the recovery movement. Psychosocial disability advocacy groups also take up projects toward the goal of social transformation, often working within and across groups with different lived experience identities. For example, the Seher programme of Bapu Trust, India, Transforming Communities for Inclusion, and Pan African Network of People with Psychosocial Disabilities (PANUSP, 2012) have each engaged in activism, on both grassroots organizing and policy levels, in relation to the Movement for Global Mental Health (MGMH). The emergence of these groups of people with psychosocial disabilities may signal a shift away from mental health advocates organizing under the user and survivor labels. Indeed, as mentioned above, PANUSP previously designated the Pan African Network of Users and
Survivors of Psychiatry; however, organizers changed their name to the Pan African Network of People with Psychosocial Disabilities (PANPPD, often still referred to as PANSUP). The psychosocial disability label was understood to be more inclusive of people who had no access to services and who were therefore not “users” or “survivors” of such services (Robb, 2012).

**Psychosocial Disability and the Convention on the Rights of Persons with Disabilities**

Those conceptualizing lived experience of madness or mental distress as psychosocial disability connect their experiences to the central tenet of the cross-disability rights movement, captured in the dictum, “nothing about us, without us” (Charlton, 1998; Cohen & Timimi, 2008). This phrase has teeth, as the inclusion of disabled people accessing services in the design and implementation of those services has become international human rights law. The formal adoption of the Convention on the Rights of Persons with Disabilities (CRPD) by the United Nations in 2006 marked an important shift in the expectations on governments with regard to their policies surrounding persons living with psychosocial disabilities, from recipients of welfare to people entitled to equality and protection under the law (Hoffman et al., 2016).

The CRPD is informed by a “social model” of disability whereby psychosocial disabilities are understood not as an intrinsic deficit located within the individual, but as a result of systemic barriers to full participation in society that are extrinsic to the person (Price, 2013). This stands in sharp contrast to the medical model, which in addition to viewing people diagnosed with “mental illness” as intrinsically deficient, positions medical treatment as a necessary intervention. Within this particular discursive formation, which frames those diagnosed with mental health issues as “lacking capacity” to manage their own
treatment and personal lives, policies have prioritized medical interventions over the right to informed consent and denial of treatment (Gooding, 2013). The CRPD instead defines disability as “an evolving concept” that “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” and accordingly, prioritizes an individual’s right to have control over their own treatment decisions. It states, “Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (United Nations, 2006, Art 17).

The CRPD and the rise of the social model of psychosocial disability has been hailed as an important step toward shifting the legal and ethical conceptions of mental health issues around the world. For example, the WHO launched the QualityRights project in 2012 to transform mental health services worldwide in compliance with the CRPD. Part of this initiative entailed capacity building, such as aiding in the development and training of local and international organizations of people with psychosocial disabilities (Funk et al., 2017). However, the majority of national and local policy and practices lag considerably behind (Hoffman et al., 2016). Some in the psy-disciplines have reacted to this rights-based approach with dismissal and scorn (see, e.g., Dharmawardene & Menkes, 2018). In particular, the CRPD committee’s statement that involuntary psychiatric treatment and denying legal capacity violates the Convention (Art. 12; 14) has been criticized by several psychiatric associations (Minkowitz, 2006), and some have attempted to position the CRPD and associated disability movement as radical so that they “may be shut out of domestic and international policy efforts” (Wildeman, 2013, p. 50).
As outlined above, the MGMH has failed to take seriously the voices, perspectives, and participation of those with lived experience from the outset (see discussion of Shukla et al., 2012). Unfortunately, this failure continues despite the influence of the CRPD. Following the 2018 Lancet Commission report presented at the inaugural Global Ministerial Mental Health Summit in London, a coalition of mental health activists and service users organized an open letter detailing their concerns (NSUN, 2018). The letter raises several concerns with the positioning of the summit, but a central issue was the lack of representation and participation of mental health activists and those with lived experience in the development of the program:

Significantly, there has been little or no involvement of organisations led by mental health service users, survivors and persons with psychosocial disabilities in the thinking, planning and design of this event. While a few networks were approached to provide ‘experts by experiences’ to attend panels on themes already decided on, there has been no meaningful consultation or involvement of user-led and disabled people’s organisations not already signed up to the ‘Movement for Global Mental Health’ agenda or funding to enable a wide range of representatives to attend (NSUN, 2018).

To sum up, the psychosocial disability discourse challenges the predominant discourses and practices of the psy-disciplines on both conceptual and structural grounds. An understanding of psychosocial disability as arising amidst a complex interaction between individuals and their environmental contexts, cultural attitudes, and societal barriers has the potential to disrupt the universal and acontextual account of madness and mental health inherent in the MGMH, and the psy-disciplines more broadly (see e.g., Spandler & Anderson, 2015). It also shifts the ethical and legal responsibility for disability away from an individual deficit to be overcome through medical intervention, and toward the forces of structural oppression that differentially afford health and illness (Dirth & Adams, 2019). In the context of the MGMH, the psychosocial disability framework may actively work against the (neo)colonial implications of scaling up concepts and treatments developed in the West,
by decolonizing assumptions about what constitutes normative or natural forms of subjectivity.
CHAPTER 3

METHODOLOGY

This chapter begins with a brief discussion on qualitative research in psychology and then proceeds with a review of Interpretative Phenomenological Analysis (IPA), the chosen method for the study. The specific research steps including population studied, recruitment methods, data collection and analysis, informed consent and credibility checks. Lastly, researcher self-reflexivity is discussed.

Qualitative Methodology

Researchers utilizing qualitative methods seek descriptive elucidation of lived experience through methods of interviewing and observing, as well as various forms of interpreting experiences; that is, they are interested in the meaning-making process of lived experience (Creswell et al., 2007; van Manen, 1990). Conducting qualitative research in psychology involves gathering rich and evocative data to better understand how individuals make sense of their world and their experiences (Coyle, 2007). In short, qualitative researchers “investigate what is experienced and how it is experienced” (Wertz, 2011, p. 125).

An important facet of qualitative research in psychology is the careful consideration of the philosophical underpinnings and assumptions of a study. Dilthey (1894/1977, p. 27)
made the distinction between natural science (Naturwissenschaften), which involves the quantitative testing of natural phenomena occurring independent of experience, and human science (Geisteswissenschaften), whereby psychological life is described and interpreted. Qualitative research in psychology, as a human science, breaks with the positivist and post-positivist epistemologies common to quantitative methodologies, instead acknowledging the role of social position and subjectivity in the research process, and viewing the production of knowledge as inherently relational and co-constructed. As such, qualitative research involves reflexivity, with the implication that researchers should report self-critical disclosure of their interests, hypotheses, personal relationship with the subject matter and their intellectual and ethical commitments (Wertz, 2011).

Critical Qualitative Research.

The central roles of positioning, reflexivity and relationality in the qualitative research enterprise points to its inherently critical (not just philosophical) underpinnings. Critical qualitative research in psychology prioritizes the perspectives, participation, and lived experiences of people impacted by prevailing power inequities (Levitt et al., 2021; Sandwick et al., 2018). However, critical qualitative methods do not flatten existing power differentials within a research collaborative, but rather bring attention to the inherent tensions of power and values in collaborations between researchers and activist communities (Fine et al., 2021). In addition, the philosophy and practice of critical qualitative research can be consistent with the ethos of the psychosocial disability movement in terms of prioritizing the “right to research,” which allows communities that have been historically excluded to impact policy formation (Appadurai, 2006). Importantly, the critical epistemology employed herein is informed by approaches to critical qualitative research on “madness” developed by
survivor-researchers, in that it seeks to disrupt normative and individualizing conceptions in favor of a recontextualization of madness based on first-hand experience (Rose, 2021).

It is important to recognize, however, that research–particularly that conducted within the psy-disciplines–has produced and sustained systems of oppression and epistemological violence (Teo, 2010). Indeed, the academic industrial complex has led to appropriate reticence and mistrust of research endeavors within both psychiatric user and survivor communities as well as in historically colonized and indigenous populations (Tuck & Yang, 2014). Therefore, to the greatest extent possible, the researcher should engage in co-participatory processes such as robust informed consent and acknowledgement of the potential outcomes and risks. Further, inclusivity in each step of the process and a willingness to diverge from prescribed psychological research methodologies if circumstances demand is essential to ensuring co-creation and co-participation both with research participants, and communities/organizations that they represent (some of which are described below). In addition, the researcher must consider the possibility that traditionally “psychological science” perspectives may prove inappropriate to accomplishing this particular project, and remain open to alternative forms of exploration, expression, and action that can facilitate or emerge from interaction with participants. The significance of these alternative forms is bidirectional–not just resulting from interaction but enhancing those interactions.

**Interpretative Phenomenological Analysis**

Interpretative phenomenological analysis (IPA) is a qualitative methodology which aims to explore in detail how participants make sense of their personal and social experiences...
IPA has its origins in phenomenology, hermeneutics, and idiography (Smith & Eatough, 2007), each of which deserves a brief mention here.

**Theoretical Roots of IPA**

Phenomenology is a specialized process of reflection and description that attempts to understand experience as it is immediately given; that is, not mediated by scientific constructs, axiomatic presuppositions, so-called common sense, or experimentation (Husserl, 1913/1998). In this way, phenomenology produces emergent data that is rich with participant experiences and perceptions and points to what makes a particular phenomenon unique (Pietkiewicz & Smith, 2014).

Hermeneutics, or what Ricoeur referred to the “theory of the operation of understanding in its relation to the interpretation of text” (Ricoeur, 1978, p. 141), speaks to the circular process whereby participants attempt to make sense of their own experience while the researcher is simultaneously attending to the ways in which the participant is engaging in meaning-making (Smith & Eatough, 2007). In IPA, this “double hermeneutic” is explicitly recognized as an essential and unavoidable feature of the research.

Idiography refers to the focus on what is unique about an individual or a single occurrence or event, and the attempt to provide a detailed description for the purpose of in-depth understanding (Ponterotto, 2005). IPA is idiographic in the sense that it aspires to a detailed examination of the lived experience presented in each individual case, even while also attending to patterns across cases (Smith, 2011).

**Stages of IPA**

There are three steps to the IPA methodology: the *epoché*, the *phenomenological reduction*, and the *eidetic reduction*. Within the phenomenological tradition, what Husserl
called the epoché is an attempt toward bracketing, or putting aside, the *natural attitude* (Gallagher & Zahavi, 2008); here, the goal is to remain continually aware of prejudices, biases, and presuppositions (Giorgi, 2009). This bracketing is not easily accomplished, for the natural attitude reveals that "I always find myself as someone who is perceiving, objectivating in memory or in phantasy, thinking, feeling, desiring" (Husserl, 1913, p. 54). We seem to assume, within the natural attitude, an “actuality” of existence (Husserl, 1913). The natural attitude makes existence factual, self-evident and a "theory-independent reality" (Zahavi, 2003, p. 44). The epoché, in contrast, can be used to make known the constitutive function of human consciousness within everyday existence.

In the present study, the researcher attempted to bracket (Epoché) preconceptions with the aid of auto-ethnographies. Auto-ethnography is a self-narrative that de-centers the researcher as an authority holding the truth about others’ experiences (Cho & Trent, 2006; Geertz, 1973). Giorgi (2009) explains that “…bracketing means that we should not let our past knowledge be engaged while we are determining the mode and content of the present experience” (p. 92). The researcher continued to use auto-ethnographies throughout the study for interpersonal reflexivity, thereby better ensuring the bracketing of presuppositions as well as validity within the research (see Walsh, 2003).

The second step, phenomenological reduction, includes procedures for returning to the lived experiences of participants ("reduction" denotes the various types of coding procedures, not the diminishment of said experience). This entails finding ways to gather and analyze descriptive data within transcripts or field notes. Data are gathered through interviewing, observing, participating (ethnography), discourse gathering and analysis, as well as self-reflection. As Giorgi (2009) writes, “Philosophically speaking, this reduction is
[…] more appropriate for psychological analyses of human beings since the purpose of psychology as a human science is precisely the clarification of the meanings of phenomena experienced by human persons” (p. 98). By the time this stage is complete, the researcher has reduced each transcript, or set of field notes (observations) to sets of concepts.

Finally, the eidetic reduction further captures the data and describes it in terms of themes or phenomenological essences. Concepts are compared between transcripts; specifically, there is a triangulation of data as concepts derived from one transcript are compared to another or concepts from one observation in the field (ethnography) are compared to concepts from other observations. The eidetic reduction proceeds by way of free imaginative variation in which the researcher imagines removing all that is non-essential to the phenomenon. This is done by constantly comparing concepts between participants or observations. The researcher places concepts together to see what changes regarding the phenomenon, and then removes what is non-essential. Horizontalization is when the researcher imaginatively places all descriptions of the experience (concepts) on one level, and therefore does not give priority to any given concept (Giorgi, 2009). Once the data have been reduced, themes are said to be structural invariants or phenomenological essences: that which must be present for the phenomenon to exist as it is.

The above process is ongoing until the researcher reaches saturation. In IPA the meaning of saturation differs from other qualitative methods, as the hermeneutic circle posits that interpretation is iterative and cyclical, whereby data can repeatedly be analyzed in light of new sources (Smith et al., 1999; 2009). In this context, saturation refers to the point where themes are “represented in a way that achieves coherence and integration while preserving nuances” (Elliot et al., 1999, p. 222-223).
Participants

Due to the idiographic focus of IPA, it is common to utilize purposive sampling where participants are selected based on prescribed theoretical criteria (Miles & Huberman, 1994). While there is no preset number of participants, it is common for IPA studies to have small samples; six to eight participants may be appropriate (Smith & Osborn, 2008).

For this study, I recruited eight participants identified as people with psychosocial disabilities with previous experience of mental health treatment in countries located in the Global South. The participants’ demographic data pertaining to age, ethnicity, gender, sexual-orientation, age and duration of mental health treatment, and duration of advocacy was recorded. No one was excluded based on age (if over 18 years), gender, race, or ethnicity.

Participants were recruited through existing partnerships with organizations that identify, in whole or in part, as psychosocial disability advocacy organizations. The researcher reached out via email to potential participants specifying the nature of the project and type of volunteer needed, and asked interested individuals to email the researcher directly in order to further protect confidentiality. They then completed a form to confirm eligibility. All confidential information was stored on a secure, password-protected computer in a password-encrypted file. Demographic forms were deleted and destroyed for any participants who were initially recruited but did not end up meeting criteria. Recruitment continued on an ongoing basis until eight participants had been confirmed.

Some of these eight were also recruited through word of mouth and snowball sampling. Snowball sampling is a form of purposive sampling commonly used in IPA due to its idiographic nature, which requires an intensive interpretive analysis of each case (Smith et al., 2009). Here, the researcher targeted participants associated with a particular identity or
experience, and then further recruited people through the associations and networks of these participants (Robinson, 2014).

Upon recruitment, participants were provided with consent and demographic forms to complete through Qualtrics prior to the interview, with the researcher available to answer any questions they may have. A time was arranged to meet over video call to conduct a 60–90 minute interview, for which participants would be paid $30 USD, distributed via PayPal within 48 hours. Beforehand, they were informed that this payment was not contingent upon completing the entire study and that they may decline to answer questions or withdraw their participation at any time and still receive payment. This information was outlined in written informed consent documents and verbally re-iterated prior to interviews.

**Data Collection**

Participant interviews lasted 60-90 minutes and took place remotely. The interviews were conducted using a secure video conferencing platform. Participants were interviewed using semi-structured open-ended questions (Goetz & LeCompte, 1984; Seidman, 1998). However, the interview format was semi-structured, with the researcher adding prompts and additional questions; these were further revised following each interview for future participants based on the experience of prior interviews. Interviews would begin with a set of prompts based on the study’s formal research questions, as outlined in Chapter 1. This method adheres to hermeneutic principles (such as the hermeneutic circle) within qualitative research (Packer & Addison, 1989). The interviews were audio-recorded with the consent of the participant, and process notes taken concurrently. All interviews were subsequently transcribed verbatim.
Data Analysis

Following transcription of interviews, the researcher engaged in several preliminary readings and listened to the interview recording (immersion). An interpretive phenomenological content analysis was then performed (Smith et al., 2009) on the data. This analysis included sorting manifest or understood obvious content (e.g., declarative, commands, qualifications), as well as coding latent content (words, strings of words, clustered concepts) that may have multiple meanings. Themes across interviews were identified and translated to a narrative account as part of the data analysis.

To accomplish this, each transcript was broken down into “meaning units” denoting units of text that are convey a discrete thought or experience. Next, an iterative process of constant comparative analysis, in a state of free imaginative variation, was utilized to compare meaning units to one another and group them according to commonalities. Lower-order or emergent themes were then constructed for each transcript based upon the meaning units contained in that theme. The intent during this first level of analysis was to remain as close to participants’ original descriptions as possible, with particular attention paid to the language used (objective comments, metaphors, pauses, tone) when referring to the experience. Throughout this process, an effort was made to account for every meaning unit in lower-order themes. If a unit was unable to be captured by a theme, this was noted in a journal of thoughts and reactions maintained throughout the analysis. When beginning a new transcript, an attempt was made to bracket themes from previous cases.

The process of constant comparison, employing free imaginative variation, was repeated for these various lower-order themes across transcripts to construct higher-order themes. During this level of analysis, the researcher again attempted to use the language of
the original meaning units whenever possible, while making a note of any idiosyncratic lower-order themes that did not find convergence across cases. When constructing higher-order themes, the researcher considered those within societal, cultural, and theoretical frameworks (double hermeneutic), attempting to make sense of participants’ sense-making (Smith et al., 2009). Special attention was paid to metaphors and language use that would allow themes to speak to the diversity of experiences across transcripts. These super-ordinate themes make up the descriptive and interpretive findings reported in the research results and, potentially, in a scholarly article.

**Ethical Considerations**

Participants retained the right to withdraw from this study at any time (i.e., consent was an ongoing process). Name(s) or any other identifying information that could possibly identify participants were not shared with anyone, with the exception of the researchers. All potential identifying information of participants has been removed from transcriptions immediately following the interview and transcription. Research records are stored securely. All audio recordings were erased at the conclusion of the research project; however, transcripts, content analysis and process notes, with identifying information stricken, will be retained indeterminately.

Some or all of the information obtained in this research project may be used in subsequent university classes, peer-reviewed articles, and professional/academic conference presentations. Any released information will be de-identified, and no publication will contain individualized interpretations of specific participants. Instead, interpretations reflect a process of content analysis and methodological triangulation that represent shared and not individual experiences.
**Informed Consent**

The process of acquiring consent involved the following:

1. There was a preliminary discussion with potential participants about the purpose, risks, and benefits of participation.

2. The researcher strove to convey information to participants such that they would be expected to be able to demonstrate their understanding of the study procedures, risks, and benefits in which they were agreeing to participate.

3. Acquiring consent included a discussion of:
   
   - Data collection and storage
   - De-identification (see below)
   - Any limits to confidential information
   - Nature and purpose of the research
   - The expected duration of the interview
   - The eligibility of the participant
   - Any foreseeable risks or discomforts
   - Any benefits to the participant or to others that can reasonably be expected
   - Confidentiality of any records that identify the participant (see below)
   - Sharing of contact information for the supervisor/researcher in the event of any further questions about the research, ongoing consent, and confidentiality

**Credibility Checks**

The researcher has had training in skillful and respectful qualitative interviewing. This involves an attempt to build rapport and create a relational atmosphere that encourages openness, sharing, and meaningful reflection. Attention was paid to the researcher-participant relationship, with the researcher journaling reflections on this throughout the interview.

Before concluding each interview, participants were asked two questions meant to assess procedural integrity: 1) Was there anything that made it difficult to answer questions openly?
and 2) Do you have any recommendations for future interviews? This feedback was used to adapt subsequent interviews.

Throughout the data analysis, a committee member with methodological expertise served as an advisor. A research assistant (another doctoral level student in psychology) was employed (through grant funding for this project) to consult and review lower-order and higher-order themes for fidelity to the original meaning units. Any questions or discrepancies raised concerning the analysis were discussed and addressed through consensus procedures, with the methodological expert assisting in making the final decision.

A written report was given to each participant outlining the invariant themes (no direct and personal interpretations of participants will be provided); like all data and written reports/papers, was de-identified. Participants were invited to review these preliminary results and provide feedback, which was then incorporated into the analysis. The researcher considered participant feedback in the construction of the results, assessing for representativeness, numeracy, and consistency with other participants’ feedback. In the event that conflicting interpretations of one or more of the themes arose, the methodological expert and researcher resolved any discrepancy, noting this divergence in the results.

**Researcher Reflexivity and Positionality**

Qualitative research values transparency and researcher reflexivity in both data collection and data analysis procedures. Methodological self-consciousness (Charmaz, 2017), or an examination of the researcher’s social location, is identified as an important part of promoting reflexivity (Harding, 1991) and emphasis on social positionality (Cho, Clarke, Friese, & Washburn, 2017). These concepts are consistent with a critical qualitative
epistemology that emphasizes that the researcher’s approach and methods, much like the object of study, are informed by sociocultural context (Levitt et al., 2021).

While I have tracked my own expectations, reactions, and assumptions by journaling throughout the interview and analysis, I also acknowledge that I come to this topic of study due to personal and intellectual interests. I am a White cisgender heterosexual male in my late twenties, who is currently a doctoral student in Counseling Psychology at the University of Massachusetts-Boston. My social location is the context from which I approach the world and I maintain and awareness of the social and cultural capital that make it possible for me to conduct this research. I have past experience conducting qualitative research and with IPA in particular. I have written previously in the academic literature and popular press about the MGMH and have critiqued its methods and aims. I locate myself within a movement of interdisciplinary social scientists who are working in opposition to hegemonic, bio-reductionist, and universalist approaches to mental health that deemphasize social and systemic issues. I am connected to networks of mental health activists with lived experience through my writing and advocacy, particularly with the social justice oriented mental health webzine Mad in America. In addition, I served as a research officer for the United Nations Special Rapporteur on the right to health, Dainius Puras, from 2018-2020, further connecting me to rights-based approaches to mental health and networks of researchers and people with lived experience seeking to reform mental health care globally. These intellectual, ethical, and political commitments inevitably influenced my approach to the research topic.

In addition, I do not identify myself as a person with a psychosocial disability or as a person with lived experience of madness or mental distress, and I have not myself been subject to institutionalization or forced treatment. In combination with my other visible
identities, position in the Global North, and status as a researcher, I am positioned as an “expert” rather than an “expert by experience.” These power dynamics inevitably shape the course and content of the qualitative interviews conducted, potentially making certain topics more salient and others less so, and influencing the language used. I attempted to address these dynamics in interviews by acknowledging differences and through questions designed to probe what might have been difficult to say. My position and lack of lived experience may also limit my analysis. While developing a pipeline for lived experience researchers is essential (a recommendation discussed later), I also believe that allied researchers can work toward greater justice in theory and practice through an understanding and incorporation of scholarship conducted by people with lived experience. For this reason, I worked to ground myself in the writing and scholarship of C/S/X identified academics.

Based on my previous engagement with this topic, I was aware that psychosocial disability advocates with lived experience may be opposed to the MGMH. At the same time, I recognized that there are currently people living with mental and emotional distress that too often go ignored or are mistreated and marginalized, and that the MGMH may contribute to an improvement in current conditions for many. As a phenomenological researcher, I attempted to bracket this prior knowledge. I was open to discovering what my participants had to say about their experiences with the mental health system, their views of the MGMH, and their proposals for alternatives.
CHAPTER 4
RESULTS

Consistent with the guidance on the presentation of IPA results (Smith et al., 2009), superordinate themes are discussed here underpinned by their subthemes. The IPA analysis revealed three superordinate themes, each of which are comprised of underlying emergent themes. The themes are presented in a structure that provides narrative coherence to the experience and highlights their relevance to the research questions (Table 1). Consistent with the idiographic focus of IPA, an interpretive account of participants’ narratives and experiences are depicted here without reference to the extant literature.

The three superordinate themes were titled: Journeying Through Different Frameworks to Psychosocial Disability Identity; Under the Psychosocial Disability Umbrella: (Re)negotiating Identities, Advocacy Goals, and Tensions; and Walking the Tightrope During Tug of War: Global Mental Health, Barriers to Inclusion, and Transformational Potential. The subthemes are not necessarily independent of one another and, in some instances, meaning units contributed to more than one subtheme or superordinate theme.

Supporting quotations are provided and participants are identified by number (e.g., Participant 1, Participant 2) to maintain confidentiality. Results of the analysis are summarized in Table 1. In addition, characteristics that would potentially break anonymity for participants have been left out of the demographic information in Table 2. For example, instead of reporting the country of each participant, only their region is identified. However,
as information about the countries referenced may be important to delimiting the scope of this analysis, they are reported together here in alphabetical order: Ethiopia, Kenya, Mexico, Nicaragua, Peru, South Africa, and Uganda. Additionally, two of the eight participants reported a marginalized identity related to sexual orientation, with one identifying as Lesbian and the other as Bisexual, but this information will not be connected to their other identifying characteristics to further protect their anonymity and reduce the risk of targeted discrimination.

The participants were all people with lived experience of mental distress and mental health treatment in the Global South who had organized their advocacy efforts under the psychosocial disability framework. In addition, all participants had familiarity with the Movement for Global Mental Health, and the majority had extensive experience engaging directly with major players in the MGMH in efforts to review or shape policies, practices, and goals. The number of years that the participants had been involved in mental health related advocacy ranged from 4 years to 20 years, with an average of 9 years. As such, the themes presented here represent the perspectives of leaders of the psychosocial disability advocacy movement from the Global South in the context of the MGMH.

Six of the eight participants responded to a follow-up survey eliciting their feedback on summaries of each of the three superordinate themes. Participants were asked to rate how well each of the three superordinate themes represented their experience on a scale from 1 (not at all) to 10 (very much) and to provide comments on how the theme might be improved. For those that responded, all three themes received above average scores, indicating their acceptability as well as their summaries (8.6, 8, and 8.8, respectively); among the six respondents there were no significant outliers. A total of 5 comments was received from
participants and their points of clarification were incorporated into the analysis. These comments largely elaborated on the summarized findings and added increased nuance to the perspectives, which is captured in the results that follow.

TABLE 1: *Superordinate Themes and Emergent Themes Across Study Participants*

<table>
<thead>
<tr>
<th>I. Journeying Through Different Frameworks to Psychosocial Disability Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mental Distress Meets the Biomedical Model</td>
</tr>
<tr>
<td>2. Seeking Recovery and Engaging in Advocacy</td>
</tr>
<tr>
<td>3. Encountering the CRPD and Psychosocial Disability</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>II. Under the Psychosocial Disability Umbrella: (Re)negotiating Identities, Advocacy Goals, and Tensions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Rethinking Identity as a Rights-Holder</td>
</tr>
<tr>
<td>2. Strategic Positioning and the Paradigm Shift</td>
</tr>
<tr>
<td>3. Uneasy Alliances Under the Psychosocial Disability Umbrella</td>
</tr>
<tr>
<td>4. Solidarity and Shared Goals Among Psychosocial Disability Advocates</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>III. Walking the Tightrope During Tug of War: Global Mental Health, Barriers to Inclusion, and Transformational Potential</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Power Imbalances in the Movement for Global Mental Health</td>
</tr>
<tr>
<td>2. Resisting Tokenization and Co-option and Pushing for Full Inclusion</td>
</tr>
<tr>
<td>3. Transforming Global Mental Health and Ending Traumatic Practices</td>
</tr>
</tbody>
</table>

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**TABLE 2: Participant Demographics**

<table>
<thead>
<tr>
<th>Sex</th>
<th>Race/ethnicity</th>
<th>Region</th>
<th>Years of advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td>Latinx</td>
<td>South America</td>
<td>10</td>
</tr>
<tr>
<td>F</td>
<td>Black/African</td>
<td>Africa</td>
<td>4</td>
</tr>
<tr>
<td>F</td>
<td>White</td>
<td>Africa</td>
<td>18</td>
</tr>
<tr>
<td>M</td>
<td>Black/African</td>
<td>Africa</td>
<td>20</td>
</tr>
<tr>
<td>F</td>
<td>Black/African</td>
<td>Africa</td>
<td>5</td>
</tr>
<tr>
<td>F</td>
<td>Latinx</td>
<td>Central America</td>
<td>5</td>
</tr>
<tr>
<td>M</td>
<td>Black/African</td>
<td>Africa</td>
<td>8</td>
</tr>
<tr>
<td>F</td>
<td>Latinx</td>
<td>Central America</td>
<td>7</td>
</tr>
</tbody>
</table>
Journeying Through Different Frameworks to Psychosocial Disability Identity

Participants described a personal journey toward identifying as a person with a psychosocial disability. This journey was varied and complex, but participants’ narratives consistently identified certain key experiences and realizations along this path. The journey began with an experience of mental distress or suffering that ultimately brought them into contact with formalized mental health services. In these services, they experienced what they saw as a biomedical approach to their distress, which provided a framework for making sense of their experience. Over time, however, this approach was experienced as limited or even harmful, and participants began to seek out different supports and approaches to recovery. Through their own recovery, and the insights gleaned through their journey so far, the participants developed a desire to get involved in reforming and improving the mental health field. All participants found their way to organizations that included other people with lived experience. Their experience as advocates revealed further problems with the mental health system, but also exposed the limits of the approaches to mental health advocacy they were working within. During this process, participants became aware of the Convention on the Rights of Persons with Disability (CRPD) and psychosocial disability framework. Participants saw the potential for this new framework to enact widespread change to mental health systems internationally, and began to organize their advocacy efforts under the umbrella term of “people with psychosocial disabilities.”

Mental Distress Meets the Biomedical Model

All participants described an experience of “crisis,” “madness,” or “mental distress” that made carrying on with day-to-day living impossible, at least temporarily. These experiences were strongly influenced by the complexities of their lives up until this point,
including their cultural and spiritual beliefs, family dynamics, and the political and economic realities of their local contexts. In one example, Participant 7 described how, after his father died when he was young, the expectation in his local culture was that he would “rise up to take care of the family,” which “placed a huge burden and a struggle” on him throughout his life. He connects the stress he took on due to this particular cultural and familial arrangement to the emergence of “back and joint pains” that the local doctors diagnosed as psychosomatic, referring him to a psychiatrist. Similarly, several participants had experiences of hallucinations and delusions that they connected with prior spiritual beliefs or understood in spiritual terms. Participant 6 described her first experience of “madness” as emerging out of spiritual experience connected to giving birth:

“I had a very deep spiritual experience 10 days after my baby was born. And if you ask the woman that diagnosed me, she's going to say that was the beginning. That was the first sign of my illness. But there's nobody that can convince me otherwise. I know it wasn't... After my baby was born, it changed me. It changed the way I see things. And then seven months later, I saw the other side of the coin. So, I knew there was plenty that was out of balance, but I knew it wasn't an illness. Even though they told me that, deep in my core, I knew, but I also knew that I had to be quiet and kind of be cooperative and not share too much.” (Participant 6)

The above quote also hints at the tension between the way the participants made meaning of their distress and the way that mental health professionals understood them. For each participant, the mental distress or break with everyday reality led to an encounter with the mental health system and psychiatry, some through voluntary outpatient services (3 out of 8 participants) and others through involuntary hospitalization (5 out of 8 participants). All participants, however, described the mental health system they encountered as primarily taking a “biomedical” approach to their distress based around psychiatric diagnosis and medication. The effect of encountering a biomedical mental health framework for explaining their experiences varied between participants and within participant narratives over time.
Several participants described access to this system as a “privilege” in the Global South and some recognized benefits, at least initially, to having a label or “framework” for making sense of what they were going through. For instance, Participant 1 explained how the biomedical explanation of their bipolar diagnosis initially reduced blame and offered the benefit of a clear solution, but they eventually came to see this explanation as disempowering and incomplete:

“I think with bipolar disorder, doctors are very attached to, ‘there is a chemical imbalance here. We need to, you need to take medication.’ There is some relief from that. The question is how much that will last. Because… every time you're reminded that this is a life condition, that this will never go away, you have to live with this, this is very similar to having diabetes, it's very similar to a cardiovascular condition, and you need to take your medication and you will be fine… you are told all of that, and of course that doesn't help, because also at the same time, you have a very fatalist view of … can I keep working? Can I keep doing things?” (Participant 1)

Similarly, medication was seen as having the potential to provide relief in the midst of crisis or intensification of symptoms. For Participant 1, being “highly medicated” led to “this feeling that you feel that is not healthy, but at the same time, I mean, you don't want to kill yourself anymore, because basically you want nothing.” As a result, he had “mixed feelings about medication” and began to come off the psychiatric drugs he had been prescribed, initially with the help of a doctor and then, eventually, completing the taper against medical advice. Beyond the immediate effects of medication, the focus on a biomedical description and solution got in the way of looking at the social and psychological factors contributing to his distress. Participant 1’s narrative exemplifies how the biomedical mental health narrative can preclude the possibility of psychosocial support. He explained that one of his doctors “told me not to do therapy,” and that the psychiatrist told him that he “felt that there is no point of talking about what you're feeling or trying to explain what brought you here, because
this is a purely chemical issue,” adding that, “If you just keep talking about this, it may confuse you more.”

The experience of being positioned as lacking insight or treated as if they could not play an active role in their own recovery, as captured in the above quote, was noted even by the participants who reported finding a psychiatric diagnosis and medication helpful. Despite viewing psychiatric intervention and medication as essential to their recovery, these participants also saw the strictly biomedical approach they often encountered as either insufficient on its own or actively harmful when their autonomy and dignity was neglected. Participant 4 described identifying with her schizophrenia diagnosis, and stated that she has found her medication regimen essential to her functioning. However, she lamented the sole focus on medication and lack of attention to the social factors that contributed to her distress and the discrimination and systemic barriers that prevented her recovery:

“Since I entered the mental health system, first of all, it was very, medical model. It was very much focused on that. I mean the first point of entry was it was immediately prescribing medication. It wasn't for me to look at all aspects of my life. It was so focused on the medical problem. Wasn't looking at, you know, how let's say my family relationships, because it wasn't very good at that time. How was that impacting on me? How am I to work? There should have been reasonable accommodations or things put in place to retain me in the workplace, because for me, my work is my purpose. It gives me purpose… it's kind of an element to recovering.” (Participant 4)

Navigating alternative understandings of their own experience while in the mental health system proved daunting and three participants brought up having to hide their views from their providers and even reducing or stopping medications against medical advice. For all participants, negative experiences with the biomedical model led to questioning the current mental health system and seeking alternative frameworks for recovery and then advocacy work. Participant 4 put it this way:
“I experienced a lot of abuse within a psychiatric hospital setting… and just the conditions were not conducive… I came to a point where I realized that, you know, all the gaps within the system and all the wrongs and things that don't work, but should work… those experiences that I had in the journey that followed was basically what led to my career in mental health advocacy.” (Participant 4)

Seeking Recovery and Engaging in Advocacy

Participants sought out psychosocial forms of healing such as peer support, psychotherapy, spiritual communities, and advocacy groups, which were central to their recovery process. These communities and psychosocial resources facilitated a new perspective on their experience. Five of the eight participants noted connecting in some way with other people having lived experience, opening up new ways of making sense of themselves and their experiences, and contributing to their recovery. Participant 8 explained:

“My situation started to change when I had access to other forms of understanding these experiences associated with mental disorders or psychosocial disabilities, specifically, beginning to be connected with other people with my same condition through peer support.” (Participant 8)

While peer support groups differed in their makeup and philosophy, one commonality reported by participants was their non-hierarchical approach. The acceptance they found among other people with lived experience contrasted with their experience in the mental health system. Participants attributed their healing and recovery directly to this experience of being treated as an equal and included in a community. For example, Participant 4 described their recovery in such a community:

“But what has helped me is, along the journey, I met a group that identified as mad people. When I reached there, what I got there was, there was love, this was not fiction, I was accepted as I am. And people were willing to help me be better, to listen to me. So that helped me. To feel loved, to feel a community, to feel on an equal basis with others. That’s what it means you to know that I’m actually unique. I cannot be exactly like others, but that was healing. I know I felt that this was an alternative to psychiatry because ever since the episodes went down and then disappeared and I even went off medicine.” (Participant 4)
In contrast, he added, “mental health workers have paternalistic tendencies… they think they know it all but, of course, when we get better, we know what is good for us.”

Others reported finding recovery and new ways of understanding their distress through psychotherapy and psychoanalysis. For Participant 1, working with a Lacanian psychoanalyst was “useful for creating my own narrative” by “going through the roots of pain or sadness or trauma… acknowledging them and, to some extent, solving them.” He explained that going through psychoanalysis “helped to reframe the whole thing and think, ‘okay, this happened to me, it makes sense why I feel like that.’… which is different than saying, ‘okay, you are just like this.’”

Participant 7 found psychotherapy in combination with other psychosocial supports helpful for recovery, including psychological support for “dealing with the trauma of my father’s death,” supported employment to “address the difficulties of poverty,” allowing him to attend school, and peer-support “where people share experiences, encourage one another… and when you have difficulties in making decisions, people are able to support you.” The support in finding work where accommodations were available that would allow them to be successful was noted as significant by several participants. Participant 3, for example, saw the “structure and routine” provided by employment, as well as the “working and serving a purpose,” as “absolutely the most important” and “the most helpful for recovery.”

Similarly, those who identified with a spiritual or religious framework also connected their recovery with a sense of purpose. Participant 2 described her “Christian spiritual framework” as a “continued source of resilience” that helped her to “see that recovery is a process,” and to “put everything in that kind of order, not expecting immediate healing, but expecting a process and a journey to recovery.” Another common theme was expressed by
Participant 6, who remarked on how important it was to her recovery to find a framework or narrative for her experience that connected her to a larger community:

“"I was lucky enough that I found myself a narrative and I've found a framework, a little bit of a framework. I haven't ended up tied to a bed again. I haven't ended up, you know, going to an emergency room again. I've been very lucky to develop a strong, strong community… I think, I'm at a different point in my process, in my journey, and I still have a lot to go through, but I haven't felt the need to search for another framework and I understand how other people might need that. And I understand the value of having those frameworks.” (Participant 6)

As participants journeyed through these different frameworks for understanding themselves and their distress, they also became increasingly involved in efforts to improve mental health care for others. Participant 3 resolved to get into mental health advocacy after witnessing abuse during her last involuntary admission:

I was in another hospital, which was really even worse than the ones I had been in before and there was really terrible abuse. The patients being physically abused, emotionally abused, all of that. And that is when, for me, it was kind of a decision and I just decided that this cannot be right. No… There must be something that one can do. So, I just made a conscious decision and once I was discharged, I decided, okay, I need to get into the mental health field. I read up a lot. I started volunteering for mental health organizations.” (Participant 3)

Despite their disempowering experiences in the mental health system, several participants noted that they were better off than other people in the system who had less privilege and social power. Participant 6, for example, cited her “mountain of privilege” as one of the reasons she “felt a responsibility to do something.” The social, educational, and economic resources available to many of the participants also contributed to their development as advocates. In their advocacy efforts, participants drew not just on their lived experience, but their professional networks, training, or creative abilities. They described building upon past training and careers in graphic design, project management, social work, and education in the social sciences and law to contribute to mental health reform efforts.
This activism increasingly revealed the flaws of current mental health systems, highlighting in particular the dehumanization of service users and lack of attention to the barriers they faced in society. When Participant 5 began working with a service-user organization, she noticed that “a service user does not have, usually, the final say in the treatment plan.” This led her to reflect on her own experiences with her psychiatrist and the fact that she had “never been given a chance to attend a consultation alone.” Instead, her family would attend with her and “they did that reporting... I'm there as a passive agent. People talking about me and not really worried about what I actually feel.” The lack of agency and autonomy afforded to her prevented her from discussing “personal issues with how I am treated in the family.” She added, “if I was given a chance, at least once, with my psychiatrist to discuss how I should handle these issues with my family, that would be a plus for me, you know, a value added to my treatment options, but it has never happened.” This realization underscored the need for user-led services and the importance of advocating for the rights and autonomy of service users. In a similar fashion, Participant 7 began working with a mental health organization to increase access to services in rural areas. However, he recalled noting that, despite a lack of access to medications, people in rural areas with the same diagnoses, “would still wake up, go to work... have a family... join, for example, if it's a lady, the local women’s club.” This observation in his mental health work led him to begin to question the assumptions of the mental health system:

“I couldn’t understand why is it that in the rural areas where we didn't have the Western psychiatric medicines, that people seem to be more a part of their society than the other people [in the cities] who had access to all these particular services... And that's actually what really challenged my thinking. I was like, okay, these people, if you look at the support system in these areas, they are quite useful. These people are working, they have farms, they are making an income... comparing the two situations also made me think that, wait a minute, whatever this system is for me, it
doesn't seem to work very well. There has to be an alternative to addressing mental health issues and distress within our context.” (Participant 7)

He began to see the biomedical mental health system as “a containment model” that “simply suppresses the way my emotional distress is being manifested in physical ways... it has nothing to do with addressing the issues that led to where I am today.” This shift challenged his thinking about his own treatment, but also led him to look for different types of advocacy work that went beyond increasing access to medication.

Several participants pointed out that they came to see their initial efforts as mental health advocates to be limited by the mental health framework and the influence of mental health experts among leadership. For this reason, all the participants began to organize their mental health advocacy in conjunction with other peers and people with lived experience. Participant 2 described her decision to advocate and share her story as a person with lived experience:

“You have to live with the consequences of what your story is and know the reason why, one is going to share their story. So, for me, it's to counter stigma. It is to counter human rights abuses... because I believe there is textbook knowledge on mental health struggles, textbook knowledge on bipolar disorder, but you, as a person having lived it, it's totally different and you have a very deep understanding that no psychiatrist who hasn't lived it or psychologists could have.” (Participant 2)

Early advocacy work for most participants focused on de-stigmatization campaigns, which often involved sharing their personal stories to highlight the possibility of recovery. As Participant 1 explained, the advocacy work most often aimed to bring attention to “stigma, discrimination, lack of employment opportunities, and patient opportunities.”

*Encountering the CRPD and Psychosocial Disability*

In the search for a more comprehensive framework, and through their engagement in advocacy, participants became aware of the Convention on the Rights of Persons with
Disability (CRPD) and psychosocial disability framework. In connecting the concept and
term of “psychosocial disability” to the CRPD, people began to also identify themselves as
psychosocially disabled or as persons with psychosocial disabilities. Participant 1 noted that
the identity is “stronger in the Global South,” with “a growing number of people that self-
identify as disabled or as people with psychosocial disabilities.” All the participants on the
African continent referenced changes in their local contexts following the CRPD that initially
signaled the potential the convention held for reforming mental health laws in their countries.
The CRPD led to processes where a country’s mental health laws came under review for
compliance with the convention, creating new opportunities for mental health advocates with
lived experience to champion reforms. Participant 7 explained that, because of the in-country
CRPD review, they “were able to get positions in different government boards working on
disability issues, on social protection, which was really, really important because if you don't
see where decisions are being made, it's very difficult to change laws, systems, policies, and
environmental programs.” Participants in Latin America explained that they became aware of
the convention from other mental health advocates, who offered trainings on the framework
as a strategy for pushing for reforms.

All participants commented on the importance of the CRPD and psychosocial
disability framework for building an explicit connection between human rights and mental
health. Participants added that the CRPD brought new legitimacy to the claims and demands
that mental health activists with lived experience have been making for decades: “the
survivor community has been saying this forever, but at least now there is a recognition from
an international standard that says our positions are just” (Participant 1). For some, reading
the CRPD was bittersweet as they reflected on how its earlier implementation might have
prevented some of their own more challenging experiences in the mental health system.

Participant 3 remarked:

“I think my first thought was that I wish it was there, in place, years ago from the beginning. At least I would have had something to fall back on and something to kind of reference when I was told I do not have any rights.” (Participant 3)

Seeing the potential for this new framework to make transformational changes in their local contexts and inspired by its recognition of the voices of people with lived experience, participants increasingly began to organize under the psychosocial disability framework.

Under the Psychosocial Disability Umbrella: (Re)negotiating Identities, Advocacy Goals, and Tensions

Following their encounter with the CRPD, participants began identifying, at least in certain contexts, as a person with a psychosocial disability. Several of them explained the identity as “a sort of umbrella term” for a wide range of people with lived experience. Under this umbrella, they encountered other people with lived experience who endorsed different philosophies and principles. The diverse identities and perspectives of different people with psychosocial disabilities brought to light stark divisions over certain key issues, including: whether existing mental health frameworks and diagnostic categories can be integrated into psychosocial disability, whether psychosocial disability contains the concept of an “impairment” or primarily stems from the societal response to natural diversity, whether forced treatment should be reduced and mitigated or completely abolished, and whether conceptions of “madness” can fit within a larger disability framework.

These distinctions impacted how participants prioritized the role of current mental health treatments in their advocacy. However, they also spoke about several shared principles among psychosocial disability advocates: calling for full and effective participation in all aspects of policy, research, and treatment; increasing supports and rights beyond access to
mental health treatment; attending to cultural factors that shape trauma and distress in local contexts; and amplifying the voices of underrepresented and marginalized groups. In this way, participants came to see the psychosocial disability identity as an inclusive term designed to welcome and unite diverse groups of people with lived experience in the interest of certain shared goals, particularly in the context of engaging with the movement for global mental health.

**Rethinking Identity as a Rights-Holder**

Coming to the psychosocial disability framework through the CRPD catalyzed a process for participants of renegotiating their own identity and sense of self in relation to the different philosophies and identities they were encountering. For Participant 1, for instance, the concept of psychosocial disability “provided a better framework to understand my own experience… through the journey of understanding where suffering comes from and how you can deal with it.”

The period of transition between different frameworks and self-understandings was often experienced as disorienting and conflicting, however. Participant 5 first interpreted her experiences as a positive spiritual and religious encounter, then came to see it as the result of a mental disorder, and was now navigating between identifying with a mental health diagnosis and a psychosocial disability identity. She described the harrowing experience of moving through these different understandings:

“So, it's very difficult, that period of transition and uncertainty, of not knowing your words, not knowing who you are really, not knowing whether you are truly worth living and, you know, finding your point of reference is very difficult. Yeah, very difficult. When a diagnosis was made and I accepted it, that was a matter of adjustment… It has never come back to the level of doubting your words, doubting even your being. So yeah, really stuck between two totally different ways of making sense of the experience. The spiritual one, in some ways it was comforting to feel like there was a meaning to the hallucinations and that was hard to give up. Then, on the
medical side, there was this plan for dealing with it that allowed a return to life and that was pretty important. But really torn between these different stories about what was going on.” (Participant 5)

Several participants noted initially feeling uncomfortable with identifying as “disabled,” and began to wrestle with different understandings of disability. When Participant 4 first encountered the term psychosocial disability, their first reaction was to ask themselves, “Am I really disabled?” explaining, “I didn’t see any disability because there wasn’t anything physical or anything, so I didn’t identify with disability initially.” As he and his fellow activists went on to attend events held by the UN CRPD committee, however, he began to understand disability differently, saying, “I realized I also experienced… the discrimination, the stigmatizing, that people with disabilities faced… so I began to identify this way.” He came to see the term disability as “even more humanizing… rather than being called a name, like madman or whatever”:

“It is more human. Because you know, humanity has disabilities, and in the diverse nature of human beings, people with disabilities are also part of the diversity. Disability is not inability. Before psychosocial disability, of course, I identified according to the medical model approach, I was a patient with a major mental illness. But then, that one also was questionable because the condition comes and goes. I am not always sick. So, I didn't want to be called a person with a mental illness when I'm actually functioning normally and I'm not in a crisis. Psychosocial disability was important. It was positive to know that, actually, you can live with a challenge. It was the positive change that I felt that other than you referring to me as a patient, a mental health patient, I do prefer to be called a person with a psychosocial disability.” (Participant 4)

Another major shift in self-understanding introduced by the concept of psychosocial disability was a transition toward seeing oneself as a rights-holder, rather than primarily a “welfare recipient,” or “mental health patient.” Participant 8 connected the process of “starting to recognize myself as a person with a disability,” to “knowing about this human rights approach,” becoming “conscious of myself as a subject with rights,” and “starting a
self-teaching process of formation as an activist.” Similarly, Participant 7 referred to the transition toward identifying as a person with a psychosocial disability as “quite radical,” adding that “this is bringing a new framing of human rights within the context of disability and the whole paradigm shift of recognizing persons with disabilities as rights-holders… rather than the old paradigm where they were viewed as subjects of charity and welfare.”

The human rights and disability framing shifted how participants made sense of what could be helpful to them, as well as their priorities for advocacy. Participant 3 began to identify many of the “external factors that are causing disability,” above and beyond the impact of her symptoms alone. She recalled being dismissed from work and being told “you will never be able to work again… never be able to live on my own, drive a car… that I always need to be accompanied… that I can’t manage my own finances,” and she now challenged this “paternalistic approach.” Participant 8 explained that he began to look around at himself and other mental health patients and “saw that their situation wasn't a lot different than mine. We all faced barriers, limitations, and our families were our basic support in our spaces for coexistence.” He added, “when I knew about this human rights approach, I finally had arguments to understand my situation of life.” The new understandings facilitated by “switching away from the medical model,” toward the psychosocial disability framework, led Participant 1 to think about his recovery less in terms of “a deficit that needed to be fixed with medication or treatment, but more like there was a lack of support that could be added that would allow me to function and feel the way that I wanted to function and feel.”

**Strategic Positioning and the Paradigm Shift**

In advocacy work, the psychosocial disability framework also led to a change in focus from repairing individual deficits to adding social supports. Several participants highlighted
that the decision to identify as a person with a psychosocial disability has a strategic element. Even as “psychosocial disability is, above all, a legal category” (Participant 1), “choosing that identity is like a political statement” (Participant 7). While the extent of one’s personal connection to the psychosocial disability identity varied among participants, all recognized its strategic potential for addressing broader barriers to health and full participation in community life. Participant 1 saw it as “a framing tool in terms of this sense of the social construct” that allows us “to better understand the challenges people face,” and leads to “broader thinking in terms of policies.” He added, “this was a very useful tool to take down and try to achieve some change.” Participant 6 also referred to psychosocial disability as “a tool to guarantee human rights… develop alternatives… and promote autonomy” that activists are using to “try to promote a movement in Latin America that uses the convention.” Participant 7 emphasized how this change in perspective meant going beyond mental health treatment alone:

“It's about moving from a narrative of providing mental health services but looking broadly at the narrative around inclusion… it's not just about mental health. What we have to realize is this debate is about inclusion of persons with psychosocial disability… it's about employment. It's about social protection… it's about access to all government services on an equal basis with others. It was sort of a change in strategy, in terms of embracing the new framework.” (Participant 7)

The psychosocial disability framework was understood as providing an advantage in advocacy efforts because of the connection to human rights and legal protections; it came with an emphasis on inclusion that was not always recognized within other forms of mental health advocacy. For instance, Participant 4 noted a difference in how he was treated when he was seen as a “mental patient”:

“Psychosocial disability has helped me in that, of course, when we are being called mental patients, we have no rights to really under guardianship laws. They were so corrupt and there was no issue of the decision-making, but now with the psychosocial
disability, even in our countries, they have to be protected by the disability act, using the CRPD. So as this group, at least we can be listened to—other than as a patient, when they have no time for you. So, I felt more human than in the medical model approach.” (Participant 4)

The newfound connection to the disability movement “re-framed a little bit of the conversation,” and created the impetus within the government to seek representation for people with psychosocial disabilities. Participant 3 was surprised that she was invited to join a governmental committee on disability and asked to represent people with psychosocial disabilities specifically. Once on the disability working group, she found she was able to use the CRPD as a standard for “advising the government on the implementation and domestication of the CRPD” with local laws. Unfortunately, inclusion did not immediately produce results. As she noted, “doing stuff for government is very frustrating because as much as you talk and advise and work, you don’t often see any change happening.” Participant 2 similarly noted that “there is no perfection in any legal framework” and that “there is a lot of work to do” to reach the CRPD standards globally. Yet she saw the emergence of the psychosocial disability framework as “very liberating.” She explained:

“I found it to be a challenge in the way we do things in my country. So, I found it to be a gateway for freedom for those living with psychosocial disabilities here. And, knowing that they're not only unwell, but they're also human beings who have rights and only need access to these rights. So, I was blown away by the discussions around the CRPD.” (Participant 2)

This quote also points to a common characterization of the paradigm shift marked by the transition to a psychosocial disability framework: from increasing access to mental health treatment, to guaranteeing access to human rights. Participant 7 referred to this as “a very radical shift” which now asked questions like, “what are the social determinants of mental health and… how do you address that also?” Participant 1 explained that the movement of a “growing number of people that self-identify as people with psychosocial disabilities” brings
with it “a strong framework of the social construction of disability… with the whole package of inclusion, [and] participation, where health is just one aspect of a set of rights, one aspect, one dimension of people's life.” Participant 8 also noted the new types of questions being asked:

“In the movement of people with psychosocial disability, at an international level, the matter of a universal basic income is being discussed, and maybe a psychiatrist or a person who agrees with the bio-medical discourse, would say ‘what does universal basic income have to do with mental health?’” (Participant 8)

In line with this shift, participants began to focus their advocacy work on programs that addressed access to employment opportunities, economic empowerment programs, and the integration of people with psychosocial disabilities into existing social and cultural programs and resources.

This shift not only broadened the discussion beyond mental health services, but also led participants to reimagine what types of mental health services could be offered that respected the rights and autonomy of people with psychosocial disabilities. Participant 6, for instance, discussed a new initiative to design “some kind of respite place for people that are experiencing non-ordinary states.” For her, the principal of self-management goes beyond treatment decisions and informed consent, to also contribute to practices like cooperativism and mutual aid where people support one another within communal and non-hierarchical organizations. As she explained: “Let's get together, you know, all of us ‘Mad,’ and we can work together to provide for our needs and we're going to decide how much we work based on how much we need for the type of life that we want to live.”

**Uneasy Alliances under the Psychosocial Disability Umbrella**

Working under the umbrella of psychosocial disability, participants noted how different personal histories with mental health treatment, as well as different political and
cultural realities, led to different identities, philosophies, and priorities among people with lived experience. Participants explained that the different groups of mental health advocates they had identified with previously, or concurrently along with psychosocial disability, were largely the result of their contexts and personal histories. Among these other lived-experience identities were service-user, Mad, consumer, psychiatric survivor, voice-hearer, and person with a mental health condition.

Several participants noted how the accessibility, social power, and stigma of psychiatry in their local contexts impacted their own experiences and, in turn, the ways they chose to identify. For example, Participant 5 explained that, in her view, the “psychiatric survivor” identity was more common in the Global North because in LMICs many people do not have access to any psychiatric services or medications. Participants also noted that the psychiatric survivor framing continues to center psychiatry in the discussion which, even if it is engaged in an adversarial way, can keep the conversation stuck in debates over psychiatric treatments and, thus, within a biomedical model. However, multiple participants went on to note that the lack of resources for mental healthcare in their countries allowed them to “walk away from services” and guessed that they might have been held against their will in the Global North. For example, Participant 6 noted: “The country that I live in played no small part in the reason that I’ve been able to get out of what sometimes can be perceived as the prison of the mental health system.”

Cultural differences in stigma and how the rights of the individual are prioritized against the rights of families or communities were also discussed. For participants in countries where experiences like hallucinations and delusions are commonly associated with demonic possession or witchcraft, they sometimes found it useful to invoke the Western
medical language of psychiatric diagnoses to reduce stigma and fear in communities. In one example, Participant 5 stated that the language of diagnosis was less stigmatizing than psychosocial disability because the word used to mean disability in the local language “is loaded with so much stigma and discrimination”:

“It doesn't have the lighter understanding and sense that you understand as an English speaker. Someone with psychosocial disability is translated in the local language as someone who is almost non-functional… language matters.” (Participant 5)

When it came to negotiating the rights of the individual vs. the collective, participants noted that advocates in the Global North often failed to appreciate the primacy of family and communal life in many other cultures. Coming from a country “where you have very scarce services,” Participant 5 explained that she found it a privilege to be able to be diagnosed as bipolar and access medications. For this reason, she stated, “I never felt myself as a psychiatric survivor, not that psychiatry has no flaws, no issues, but… for me, [service-user] emphasizes more of the active agency, way more than the mistreatments.” She then added:

“Maybe in the Western world, you have a very individual culture, right? You advance concepts of rights that you think that you have and that you are being deprived of when you are involuntary admitted, et cetera. But for me, I am really grateful for my parents and my family for involuntary admitting me because I would have lost so, so many things.” (Participant 5)

Participant 5 also noted that “families are the natural form of support,” and that when in periods of distress, “most likely it is my family that will take responsibility for that.” These quotes highlight how lived-experience advocacy groups that prioritize the right to refuse medication and to make individual decisions over treatments did not resonate with participants from the Global South where few people have access to medications, psychiatric institutions have less power to institutionalize people, and where familial and communal decision-making practices are more widely accepted.
Participant 5’s reference to involuntary treatment also alludes to the disagreements over certain principles, definitions, and priorities between different subgroups of people with lived experience who now identify as people with psychosocial disabilities. All participants discussed how, through engaging in advocacy work under the psychosocial disability umbrella, they encountered a more diverse group of people with lived experience and, as a result, became increasingly aware of different perspectives and disagreements. As Participant 7 put it, “the issue of identity peels over into issues of ideology and the way you perceive things and the kind of standards you want to uphold.”

**Impairment, Diagnosis, and Disability.** On the broadest level, there was disagreement over whether psychosocial disability could integrate parts of a biomedical mental health approach or whether psychosocial disability constituted a clear break with this approach, and was therefore incompatible with notions of psychiatric diagnosis. Participant 1 explained that some psychosocial disability advocates had come into the movement with opposing goals:

“From my experience, you have different ways that people came into advocacy. Some people from a perspective of a service user and basically demanding sometimes just access and more often better quality of services, but still in the belief that mental health services are important and should be available and should be accessible… framed strongly in the right to health framework. Then you have a survivor community that has been harmed by the system and by psychiatry that normally has a stronger stance... some of them actually have a perspective that psychiatry has no role and that mental health services produce more harm than good. So, you can see that there is a completely different position for those advocating for mental health services and those that are advocating actually for reparations to the victims of mental health services.” (Participant 1)

Indeed, each of the participants located themselves somewhere on the spectrum between those with integrationist perspectives on the biomedical model of mental health, who want to
increase access to services globally, and those on the more radical end who focus instead on building alternatives to psychiatry.

The question of whether the psychosocial disability framework should integrate what was alternatively referred to as psychiatric discourse, mental health frameworks, and the biomedical model is most apparent in the debates over “impairment.” Within the social model of disability, any disability is understood to arise from social barriers and the lack of accommodation of the physical difference, or impairment, of the disabled person. However, the participants pointed out that disagreements remain over how to describe and conceptualize what it is about the person that is not being accommodated within their environment, thus causing the disability.

Those who saw their own diagnosis as accurate and helpful integrated the biomedical model by equating the psychiatric diagnosis with impairment. For these participants, diagnoses such as schizophrenia and bipolar disorder referred to universal underlying medical conditions and then disability arose because of social stigma, discrimination, and a lack of support for people with these conditions. For example, on the issue of impairment, Participant 5 drew an equivalence between psychiatric diagnosis and physical disabilities, going so far as to say that she preferred the term “mental illness” to “mental disorder.” She added:

“Because when you say disorder, you have an order... and you have something not going as ordered. It has some negative connotation for me. But when you say illness, it has some parity with even a physical illness…I prefer to describe myself as someone with bipolar disorder… It's part of my personality, you know. It's who I am. It explains my mood swings. It explains my actions, my emotions.” (Participant 5)

Participant 2 said that some psychiatric diagnoses might vary by context, giving the example of different sexual orientations being seen as disorders in her country but not in the West.
Other disorders, however, such as depression and bipolar disorder, she saw as appearing the same everywhere, “irrespective of the place of treatment.” She explained that because “the science is universal,” certain psychiatric diagnoses could be understood to be “part of human nature.” When considering the link between psychiatric disorders and disability, Participant 3 also made the comparison to physical illnesses. She explained:

“For me… the existing condition is still there. And is it impacting on my mental health. So, when you look at external factors, what society causes, it just makes it much more difficult to manage. They're seeing me as different. I think I know a lot of people don't like to compare it to physical illnesses, but, if I have a headache, you know, nobody's discriminating against me or anything like that. But if you say you have a mental health condition, all of the sudden, it's a completely different thing and it shouldn't be.” (Participant 3)

However, she accepted that social factors do not just factor into disability in response to an underlying condition, as these social determinants can also be one of the causes of mental health conditions in the first place. In her words, “mental health is so complex because there's so many factors… whether it's inherited disease in your family, a mental health condition can be caused by trauma or stress. There's just so many causes. I can't really say that there's particularly one thing that causes those things. So, for me, it's a combination.” Despite all the various causes she saw for mental health conditions, she felt that “even within psychosocial disability,” it is still important to “link the mental health conditions to it” and “add that component of that medical side to it.”

For these individuals, the analogies to medicine and physical disability were both seen as useful for efforts to reduce stigma and discrimination. Participant 2 argued that a “transformation at the community level happens when you simplify psychosocial disability”:

“Everybody's like, ‘Oh, okay. So, it is actually a disability. This is not something that you brought upon yourself or some flawed thing that you've done… It's a sickness that has come
upon you, it's an illness and one needs care like anybody else.” When doing outreach work on psychosocial disabilities, she liked to use the example of a broken arm, saying “the same way that when you wound your arm, you need support to heal, the same way the mind needs support to heal.” This comparison alludes to the possibility of recovery, breaking with other comparisons to medical illnesses that imply chronicity and the need for medication management, such as in the common “like insulin for diabetes” idiom for depression. The possibility of recovery was also discussed by Participant 4. He defined people with psychosocial disabilities as “people who have had chronic episodes with mental health challenges that reduced their capacity to function on an equal basis with others,” adding, “the condition comes with barriers that will not enable you to function and that is where disability comes in.” However, he explained that the “mental health challenges” implicated in impairment were likely to come and go or change over time: “If you call me a person with schizophrenia, it doesn’t mean I’m always schizophrenic… that diagnosis is not permanent… maybe I come out of it and then have depression or bipolar… but you can change so I don’t see why labels should be there.” He compared this to a person with a psychosocial disability who, even when “they have recovered, they can still identify in that way because they have faced discrimination in the past, lost jobs, and had long term impairments that changed their life.”

In contrast, participants who were critical of the biomedical model experienced psychiatric diagnoses and comparisons with illnesses as limiting and stigmatizing in themselves. For Participant 6, for instance, “the biomedical narrative… it’s damaging to people,” and those who use that narrative, “they talk about stigma, stigma here, stigma there, but they don’t see that the stigma starts with the labeling and the mainstream narrative.” A
recurrent theme that came up with these participants was that integrating much of the
language and concepts of the mental health framework would undermine the potential of the
psychosocial disability movement to push for supports beyond access to medication and
therapy. Participant 7, for example, argued that when advocates attempt to bring the
biomedical framework into the conceptualization of psychosocial disability, they risk
translating social issues into mental health issues. He gave the example of gender-based
violence, saying “if someone is in an abusive relationship, there’s no medicine that’s going to
fix that… we really have to address gender-based violence.” By treating the effects of this
abuse as a mental health issue advocates can inadvertently collude with the “families, people
in communities, and local administrators that want to cover these issues up.” The advocates
who focus on a mental health framework get it backwards, he argued:

“The narrative for them is like, ‘if you want to fix education, you have to fix mental
health. If you have to fix up issues about employment, you have to fix mental health.’
But for me, it's not like that…. The whole issue of me being able to be in an
employment space more or less has nothing to do with my mental health. It's about
creating accommodations and support systems within the workplace.” (Participant 7)

This concern is connected to the issue of impairment because if impairment is defined
narrowly and in biomedical terms, it tends to lead to an exclusive focus on medication access
and adherence. In response to this issue, participants suggested defining impairment broadly,
in terms of some difference or diversity that leads to marginalization in society and then, as a
result of these social barriers, leads to disability. Participant 1 explained:

“I think when joining medical framework, that's what you hear every single day…
repeated by doctors, families, and everything. You need to keep your treatment, you
cannot abandon treatment… without that realization that maybe we are more complex
persons and that we have these different needs. So, this is also about embracing, I
would say, diversity. I think for me, that's an important concept: the diversity of
emotions and embracing the diversity.” (Participant 1)
Because some lived experience groups do not identify as disabled, seeing this as tantamount to an admission of impairment, some advocates have suggested that psychosocial diversity might make a better umbrella term. However, Participant 1 also noted that without a stronger definition of difference, diversity, or impairment, the psychosocial disability identity becomes conceptually dependent on the existence of social barriers.

“Which other groups define themselves in terms of social barriers? Which is weird, because… if society is inclusive and accessible, do you lose your identity? … my point is that maybe we need to focus again on the diversity aspect of it… We should embrace it and understand that there are social barriers and we need to take them down and discrimination, but I wouldn't like to be a person without disability.” (Participant 1)

For this reason, he preferred the term “madness” to impairment and suggested that theorizing impairment in terms of “madness” would lead to more radical social change for psychosocial disability advocates than integrating biomedical conceptualizations and diagnoses from psychiatry. Similarly, other participants suggested that impairment can be better conceptualized by new terms that do not carry the baggage of medical discourse. For instance, one person advocated for terms like “sentipensantes” (feel-thinkers), which better captures how those deemed “mad” connect “the rational and emotional,” as well as “psicodisidentes” (psychodissidents) “because we as activists assure the idea of madness as part of our identity, and as part of political discourse, we are dissidents of every social norm.”

Without bringing in the biomedical explanation for etiology, these advocates left open the question of where difference, impairment, diversity, or madness originates from in the first place. Participants acknowledged that this was a politically fraught question, with myriad contrasting opinions among people with lived experience internationally. For this reason, several participants stated that sometimes it is best not to address questions of
causation openly. Participant 1 stated that “we don’t really go too much into that,” especially, “because rights shouldn’t be dependent on that and, anyway, the convention protects people no matter how they perceive impairments.” Participant 8 worried that giving too much attention to the causes of impairment would be strategically unwise for psychosocial disability advocates because these theories have historically been used to “justify inhumane treatment,” saying “it’s best for advocates to avoid theory about madness or impairment and where it comes from.”

Coercion, Forced Treatment, and Institutionalization. All participants referred to ongoing tensions over coercion and forced treatment in mental health settings, emphasizing that the largest gap on this issue was between advocates supporting the CRPD and organizations representing psychiatrists internationally. Participant 7 explained that the transition to a rights-based approach to mental health, which had been inspired by the CRPD, has been held up, largely, due to “resistance from medical professionals” and “organizations of psychiatrists.” Similarly, Participant 8 noted that “there is a lot of influence from psychiatry against recognizing the full rights of people with psychosocial disabilities,” because of “the idea of a lack of mental capacity, the incapability to express our own will,” which, he added, is “something that doesn’t happen with physical disabilities or sensory disabilities.” All of the participants acknowledged that it was their goal to reduce forced treatment, and increase shared decision-making and informed consent practices. They noted disagreement, however, on how to go about achieving this and on whether forced treatment should be completely abolished. In putting forward their positions on this topic, several participants spoke with hesitancy, acknowledging the complexity and the weight of the issue and reflecting on their own experiences with coercive practices.
The majority of participants (5/8) described having experienced coercion in a mental health setting, including being chained to a tree, placed in physical restraints, forcible injection of sedating medications, coercive treatment, threats from hospital staff, ECT without informed consent, being held in a medical facility against their will, and long-term or chronic institutionalization. All three of the remaining participants detailed witnessing coercive treatment in their advocacy or mental health work and spoke about being shaped by what they saw. Participant 1, who in his advocacy work has visited psychiatric facilities internationally for 15 years, noted how widespread and common coercive practices are worldwide:

“You would see people deprived of their liberty for a long time, neglect, a lot of situations that you will consider torture… absolute lack of support… people in secluded rooms for years, people tied to their bed… around the world it’s the same.” (Participant 1)

Another participant (ID number omitted here to further protect anonymity) shared her own story with forced treatment, coercion, and institutionalization. She disclosed that the first time she was involuntarily admitted, she was explicitly told she no longer had any rights.

“I was directly told I have no rights. I have no human rights. I'm the property of the president. I'll never forget it. My signature means absolutely nothing. So that really kind of bulldozed me... I was already struggling, already felt worthless because of the stigma attached, and fear about how people are gonna treat me because of my mental health condition. I go to a place that's supposed to provide me safety and care and now it further strips me away of who I am, my person. So, for me, I didn't even know at the time that I could put up a fight. They couldn't do it to me today. But back then, I didn't know. I wasn't aware that I had rights. I just believed them. I think that impacted on my recovery. Absolutely. Because, I mean, if you feel worthless, you're not going to fight or try to better your life or anything. I just gave up really.”

Once involuntarily admitted, she was transferred to a “lockup ward” where she was told she would be held indefinitely. She was stripped of her clothes and her possessions, taken to a dormitory with 40 other women, threatened by a nurse and then forcibly medicated. She
recalled waking up to the sound of the keys unlocking the doors in the morning. “You're locked in the dormitory at night,” she explained. “So, in the morning, they unlock you, it's from door to door they lock and unlock you. I still struggle to deal with the sound of keys. It's like the prison keys.” After being lined up naked in a queue to be bathed, she was then locked in the breakfast room, “then for the rest of the day, they lock you in a huge room, but it's only concrete floors.” Heavily sedated by medication, she and many of the other patients slept on the concrete floors throughout the day. She summed up the experience:

“I think it was probably a more traumatic experience than the symptoms I experienced from my diagnosis… I still have flashbacks. I'm often triggered by specific sounds and tastes, you know, from a moment I had in there… the feeling of the cold floor, the keys. To this day, I will not close, I can't close, a door. It just freaks me out…. It's all those things and it's like what 20 odd years ago. It's still with me.”

These personal encounters with forced treatment and coercion informed the advocacy goals and positions of participants. Despite her own traumatic experience, the participant above did not take an abolitionist position against all forms of coercion in all situations. Instead, she suggested the coercion should be reserved only for crisis situations where a person poses an imminent danger to themselves or others, should be as brief as possible, and that once in treatment, rights should be respected and protected. She warned that if forced treatment were abolished immediately, it would lead to people in crisis being criminalized and sent to prison where they would be less likely to be protected by the CRPD.

Another participant stated that she was grateful to have been forcibly medicated against her will during what she described as a manic episode, despite how painful this was for her:

“No manic episodes, I have done so many exuberant things that I am always ashamed of afterwards. So, if my parents weren't there to tie me, to chain me in, to take me to the hospital, to be treated there, things would have escalated, and I even wouldn't be alive today. That's how I understand it. I'm very grateful for my parents
to cross the line, the border of individual rights, liberty, et cetera, for my best interests.”

She added, however, that “to be treated forcefully is painful,” adding:

“I know because I have some fresh memories in my mind where people are tying me, strong young men, with muscle, pulling me, my hands behind, so that the nurse could inject some calming medication, et cetera. That memory is still fresh in my mind, and I don't like it. I don't like it, but retrospectively, if that hadn't happened, the sequence would be much worse.”

Because of her own experience, she explained, she does not take a bold stance against all involuntary hospitalizations in her advocacy. But even in these circumstances she “condemns treating the service-user with disrespect,” which, she added, is “very common but not at all fair.” She then raised the issue of legal capacity, asking “to what extent can we leave it to the individual to exercise his or her right, even when many others feel they may lack the ability to make an informed decision at that moment?”

The question of legal capacity came to the fore for other participants who saw this issue as having consequences that ripple throughout society, far beyond the walls of mental health institutions. For instance, Participant 8 stated that the idea of “lacking legal capacity” goes well beyond crisis situations and ends up justifying coercive practices throughout the mental health system:

“In psychiatric discourse, psychosocial disabilities are associated with the idea of a lack of mental capacity, the incapability to express their own will, the difficulty to recognize oneself as a subject that interacts with society… Because of this, people with psychosocial disabilities are submitted to treatments against our will, involuntary interventions are imposed on us that in some cases can be irreversible, such as sterilizations, electro-convulsive therapies, a series of practices that in other kinds of individuals could be seen as unacceptable, but, the psychiatric discourse has made society consent to the imposition of these treatments on people that are seen as ‘mentally ill,’ this also validates the existence of ‘madhouses,’ as well as the
existence of the presence of a powerful pharmacological model in our day-to-day life.” (Participant 8)

Similarly, Participant 7 saw the question of legal capacity as “leading to rampant human rights violations,” and “reinforcing stigma,” which “entreaties deep discrimination.” He gave the example of criminal and legal codes in his country that prevent people with psychosocial disabilities from entering contracts or even getting married. In another example, one participant noted that in her immigration documents to gain citizenship in a high-income country she had to answer the question, “Have you ever been in a psychiatric institution or legally incapacitated?”

“It was under the moral character chapter. Like before they were asking me if I had supported terrorist organizations and later if I had been convicted of any child trafficking and then, in the middle, you have this.”

On the issue of legal capacity and forced treatment, Participant 5 underlined the necessity to come up with solutions that balance conceptualizations of “individual freedom,” which she associated with the West, against “the best interest of the person,” as determined by the family and the community, which she stated was the most common consideration in her country. “You have two extremes that are not working for the service users,” she added. “So, there should be some middle ground to that.”

Participants saw room for such a middle ground on the major issues dividing people with psychosocial disabilities. In doing so, they often acknowledged that other advocates had come to their beliefs honestly, through difficult situations, and recognized that debate over these issues was not just abstract, but personal. Participant 2, who identified as a service-user and a person with bipolar disorder, as well as a person with a psychosocial disability, agreed that “people who have had good treatment are usually maybe more okay with using mental health language and people who have had bad experiences with treatment, like psychiatric
survivors, feel that their treatment was something they had to escape from.” However, she saw their experiences of bad treatment not as a result of the biomedical model but potentially resulting from a lack of access to “early diagnosis, good diagnosis, and good treatment.” Conversely, Participant 8 advocated for moving away from psychiatric discourse, but spoke about how challenging this discourse can feel like an “attack” to other service-users that leads to infighting rather than the desired social change:

“It is a complex process because… psychiatric discourse has such power that there are no alternatives that are allowed to people who are in a lot of distress, with a lot of mental pain, that are socially excluded. This makes it so that a lot of people who are users of mental health services normalize all that discourse, and when you question those approaches, they feel attacked. They feel like suddenly their world collapses and instead of starting a process of analysis and self-recognition, positioning themselves inside that discourse and recognizing themselves as a subject of rights, in a lot of cases they question us, those who are questioning that model, that approach and evidence.” (Participant 8)

Due to the personal nature of these issues and the resultant strong positions taken by various advocates, participants argued for a form of pluralism, recognizing that, as Participant 6 put it, “if we try to impose our views on each other, we are recreating the problem ourselves of oppressive power dynamics and hierarchies.” Instead, she resolved: “my view is my own and everybody has a right to their view… and we need a respectful place to accomplish our shared goals.”

**Solidarity and Shared Goals Among Psychosocial Disability Advocates**

Even as the heterogeneity of perspectives under the psychosocial disability umbrella posed challenges for advocates, participants emphasized the benefits of uniting people with lived experience within a human rights framework. Participant 3 also highlighted the importance of respecting a diversity of viewpoints among advocates:

“Thinking about the different groups in the user, survivor, psychosocial disability movement, and the different sort of philosophies about mental health that are there; If
there was more acknowledgement and less infighting, it would help to make more policy influence on a larger scale. It's likely you cannot force people to kind of believe what you believe. It also comes back for me to respect and appreciation for diversity.” (Participant 3)

In this regard, participants underlined several key principles and advocacy goals that were shared among most people with psychosocial disabilities. First, participants agreed to a broad definition of psychosocial disability built on the social model, as long as it avoids specifics about the issue of impairment. Participant 8 summarized the widely agreed upon conceptualization this way:

“According to the social and human rights model about disability, we can say that disability is a situation. In this situation, there is a person with a functional condition that puts them in a minority, and they have faced discrimination and barriers as a result. This is also valid in physical disability, in sensory disabilities, in intellectual disability. From the social and human rights model, the disability becomes a legal category, a person or user of mental health services is at risk of being discriminated against because of a condition or disability because they are seen as different.” (Participant 8)

Within the framing, participants agreed that “there is so much to gain” by adopting this framework and connecting with the broader disability movement, especially, as Participant 7 put it, “in terms of transforming and then ensuring the full and effective participation and inclusion of persons with psychosocial disability.” Connecting with the disability movement creates opportunities for people with lived experience to have a greater influence on research and policy surrounding mental health, but it also means influence on (and access to) broader social programs. For example, participants became involved in economic empowerment programs, education support programs, and departments on youth welfare, to name a few. As Participant 7 explained, the psychosocial disability framework “creates structures that will enable the empowerment and the full and effective participation and inclusion of persons with psychosocial disabilities on an equal basis with others in all facets of this country.”
The emphasis on particular interactions between the individual and social barriers in the construction of psychosocial disability facilitates a shift away from a “one-size-fits-all approach” to addressing mental distress. Participants envisioned a system where people in distress could choose from a menu of supports that would help them return to life. Instead of presenting with distress in a medical setting and entering immediately into mental health care to be prescribed medication or inpatient or outpatient treatment, there would first be an attempt “to find maybe other causes of what kind of triggered a mental health problem and first trying to resolve those issues” (Participant 3). Then, people might be empowered to embark “on a more personal journey in terms of how different people feel and what does support mean to them,” which in the short term could mean, as Participant 1 stated, help with “communication, supported decision making, peer support, normally some mix of all of this, understanding that you may not feel well and you may need help from friends and peers.”

Even participants who were critical of the biomedical approach or chose not to take medication themselves went out of their way to emphasize that they are not anti-medication, and that they support others who may choose medication in the short or long term. For example, Participant 3 stated that she believes she will need life-long medication to manage her psychosis symptoms for herself, and wanted to make sure these drugs were available to others who currently did not have access. “What I don’t agree with,” she added, “is a psychiatrist or doctors going too easily to diagnose or too easily just to prescribe medication… when you never even looked behind the psychosis… what are the reasons for me?... what kind of triggered my mental health problem and first trying to resolve those issues.” Participant 8, who conversely refused medication for his own symptoms of mania, outlined a similar perspective.
“Something fundamental is that, in the end, there’s certain accord that we as activists don’t question when others decide to take a pharmacological treatment, or even in a situation of crisis if they choose to be under supervision in internment. The problem is that the people don’t get information, that there are no alternatives, that they imposed the decision, that their rights don’t get respected. In an ideal state, maybe psychiatry would be an option in a spectrum of alternatives, and not as it happens now that it is the only option available or even is imposed on a person who is living a critical psychosocial situation.” (Participant 8)

Participants also highlighted how the available supports “in a spectrum of alternatives” can and should vary by cultural context, including local community and religious organizations and traditional healers. Participant 7 explained how traditional healers can play a key role in addressing issues in their country. As trauma and distress can often arise due to circumstances within a family or community, traditional healers who are more closely tied into these networks can often identify and address the underlying conflicts in a way that mental health professionals cannot:

“If you got to a traditional healer... she would ask them about… family problems, relationship problems... and that for us was a different way of addressing people’s distress and trauma.” (Participant 7)

Participants also stated that, depending on circumstances and local context, people with lived experience might choose not to identify as a person with a psychosocial disability. Because of the way the psychosocial disability framework has been broadly defined, advocates saw their work as “raising up the voices of other marginalized groups” and “putting in play this legal mechanism to fight this discrimination.” “It has to be a process of coexistence,” Participant 8 said, “a slow process in which we accompany each other and recognize ourselves as a collective, a collective that faces the same barriers independently of the ideology of each member.”
Walking the Tightrope in a Tug of War: Global Mental Health, Barriers to Inclusion, and Transformative Potential

The final super-ordinate theme emerged from participants’ descriptions of their reflections on the Movement for Global Mental Health (MGMH) and their experiences engaging with leaders of the movement. These included becoming involved in MGMH research initiatives in their local contexts, and navigating the relationship between MGMH-affiliated organizations and psychosocial disability advocacy groups of which they were a part. One participant described an ongoing “tug of war” between leaders of the MGMH and their critics, while another felt that they were “walking a tightrope” back and forth between “totally different ways of seeing.”

All participants identified issues with the MGMH on conceptual and practical grounds, and discussed how divisions within the larger psychosocial disability community impacted their advocacy efforts. As psychosocial disability advocates, several participants faced a difficult decision between engaging in a “tokenized” role while attempting to push for reforms and CRPD compliance, or refusing to engage out of principle and risking the implementation of oppressive policies without their input. Participants outlined necessary guidelines and best practices to create the conditions necessary for the full and effective participation of people with psychosocial disabilities in the MGMH. If these conditions could be met, they were optimistic about ending traumatic practices and transforming the MGMH toward a rights-based paradigm. In addition, participants saw the psychosocial disability framework as having the potential not just to create solidarity “under the umbrella” between different lived experience groups, but also to facilitate new partnerships and alliances with other disability and human rights organizations. These collaborations can be leveraged to put
financial, legal, and political pressure on MGMH projects for full inclusion. Their hope was that a full integration of the psychosocial disability framework into the MGMH efforts could create a paradigm shift away from scaling up the biomedical model and toward implementing rights-based policies, research, and interventions.

**Power Imbalances in the Movement for Global Mental Health**

Participants stressed the many barriers that people with psychosocial disabilities face to full inclusion and participation in the MGMH, including a lack of reasonable accommodations and power imbalances between “experts” and “experts by experience.” To highlight the type of expertise that comes with lived experience, Participant 5 drew on consumer metaphors, saying: “if you want to know how comfortable a bed is, you don't ask the manufacturer, you don't ask the retailer, you ask the one who sleeps on it on daily basis. He knows where it hurts. He knows where it needs some work to make it more comfortable.” Acknowledging that the expertise users have about their own experiences extends beyond their experience of services, the consumer metaphor is nonetheless illustrative and ironic. It draws attention to the perception among participants that the MGMH was entangled with the commercial interests of psychiatric and pharmaceutical institutions that viewed them less as sources of essential knowledge, and more as unwitting customers of a product.

For instance, when participants pushed for compliance with the CRPD in their advocacy work, they found that this framework, while supported by disability and human rights groups, was often actively opposed by powerful psychiatric organizations and pharmaceutical interests. Participant 7 relayed that “there was a lot of tension between mental health professionals that were not willing to adopt the paradigm shift.” A few participants noted the explicit statements put out by organizations of psychiatrists that contested the
human rights and psychosocial disability framework, particularly with regards to the prohibition of forced treatment and the recognition of legal capacity. The resistance of the psychiatric community presented a major barrier to the reform efforts being championed by psychosocial disability advocates due to the outsized influence psychiatric and pharmaceutical groups had on governments:

“You really have to recognize that psychiatry has a huge influence and especially working closely with pharmaceutical industry… that's a huge, huge problem because they will come in, you know, influence a lot of things because they have money, they have networks, they can lobby, they can see the government anytime they want. Unlike me, who it might take a lot of time before I see even a junior staff member... So, we also have to look at the power that psychiatry has with a lot of backing from pharmaceutical companies to do their work, of course, in the global south.” (Participant 7)

Participants also described encountering this power differential with psychiatrists, psychologists, and other mental health professionals in interpersonal situations where there was meant to be equal collaboration. Participant 2 noted that, “there is always some tensions there,” because “psychiatrists feel like they have certain abilities and are above the users.” Participant 8 relayed a story where he was invited to speak about his recovery by a psychiatrist at an institution where he was previously held. When he explained that he no longer identified with his diagnosis and would instead present on how he came to understand himself as a person with a psychosocial disability, he found that the psychiatrist was unfamiliar with the CRPD. After sending him a copy of the CRPD, the psychiatrist replied that he “wouldn’t trust any book without a bibliography.” “Obviously, I told him that we were talking about an international tractate about human rights. The Constitution doesn't have a bibliography at the end for consultation.” In this way, he felt that the psychiatrist was attempting to frame their disagreement in terms of “psychiatric science” versus “values and beliefs.”
The power dynamics between “experts” and “experts by experience” were exacerbated by, and entangled with, the historical and ongoing exploitation of the Global South by the Global North. As psychosocial disability advocates in the Global South, the participants recognized that the priorities, methods, and leadership of the MGMH stemmed from the Global North. Participants observed that many of the MGMH projects in their locales were based out of the U.S. and UK, did not actively involve local experts or communities, and that their financial resources only “trickled down” to local organizations. For example, Participant 7 explained that his organization “has withdrawn from some of the projects because of that issue,” saying, “you can’t be telling us to implement your projects here in [African country] when most of the resources and manpower is based in London or New York or whatever.” For many participants, this arrangement was reminiscent of their country’s history with colonialism. Participant 6 explicitly referred to the MGMH as “the grandchild of the colonialism of 500 years ago.” She explained that “in Latin America, we’ve had dictatorship after dictatorship, extractivism, the United States on top of us and all these military interventions because of that… free trade agreements where workers are paid under minimum wage, they have no rights, they count the times they go to the bathroom, just horrible conditions.” She saw the MGMH as operating from the same logic as these other policies brought to the Global South by the Global North, saying “it’s just a newer manifestation of that white supremacism, egocentric view of: ‘we know it, this is the universal truth and we know and this is it and we're going to help you, we're going to bring you to our level.’” Participant 5 also drew an explicit link between the Global North’s extraction of resources through slavery, mining, and the ongoing exploitation of labor in her
country, and the way that MGMH researchers come to “mine data” and pursue donor funding
to support their academic careers:

“There is a power dynamic going on between the South and the North. Sometimes
you'll see how things are done and you wonder if truly the North really seeks the
South's best interest. Sometimes it's a matter of livelihood as well. I can say that
frankly, I have no reservation on that because I am convinced it's how it works,
actually. So, you have scholars, researchers that come to the South to mine data from
the people's distress and they are in their comfort zone in a well-furnished house in
their offices with their own software and well-established systems to analyze the
distress of the people in the South that they have no comprehensive idea about.”
(Participant 5)

Seeing this arrangement and being involved in some of these projects, she began to ask, “is
this meant for keeping up the livelihoods of Western researchers and technocrats, or is it
really meant for me?” Through her experiences in these projects, she came to believe that the
researchers cared about “meeting the donor project outcomes, not really what is truly needed
to make a breakthrough.” She asked: “If everyone was flourishing, as we wish it on paper,
what would become of everyone doing the PhD and masters in global mental health?”
“Well,” she said, “they might become very poor people.”

A recurring criticism was that MGMH experts did not fully understand or account for
local cultures and beliefs in the Global South. Participant 7 was involved with several early
MGMH projects in his country based out of “leading universities” in the Global North. He
came to see that the researchers did not attempt to understand local practices, laws, or
traditions because they “assumed that Western medicine would sort of fix the mental health
problems or distress or trauma going on in Africa.” He explained that the MGMH researchers
would “design the questionnaire, the methodology, and they are based on Canada and
Australia and all that, then bring in a researcher from that country to do the research.” After a
short time, he became “really, really against these design frameworks,” saying that “come on,
you don’t live here, you don’t understand the legal frameworks, you don’t understand the politics of social change in this particular country and I find that to be very, very problematic.”

The participants saw the inclusion of a diverse range of local people with psychosocial disabilities as having the potential to disrupt this top-down approach in global mental health. Groups and organizations made up of such people, when included, have expertise on their own local contexts and treatment experiences in those contexts. As a result, they are well positioned to aid in adapting or transforming the research to be more responsive to the nuances of cultural experience and contextual factors. Participants also recognized local obstacles to the improvement of supports for people with psychosocial disabilities, including stigmatizing beliefs and corruption in local governments, that needed to be addressed. However, they spoke of resenting the narrative that because there is stigma and abuse in their local contexts, a Western model of mental health needed to be imported wholesale while ignoring the stigma and abuse that occurs within that model.

**Resisting Tokenization and Co-Option and Pushing for Full Inclusion**

Following the CRPD and the development of regional groups organizing under the psychosocial disability framework, the participants began to be invited to participate in global mental health projects. They often found, however, that this participation or representation was not the same as the “meaningful and authentic engagement” they were seeking. Participants detailed a number of practices by MGMH groups that created barriers to the full inclusion of people with psychosocial disabilities in the process. These ranged from subtle put-downs to what appeared to be deliberate attempts to “tokenize” and “co-opt” their contributions.
Related to the power dynamics discussed above, participants identified feeling less-than and othered in their interactions with experts in the MGMH. Sometimes this was reinforced by being reminded to call the researchers by titles, like doctor or professor, but other times it emerged in subtle interpersonal interactions. Participant 2 described it as “being in those little interactions with people who try and make you feel as if you are not one hundred percent a human being when they realize you struggle with mental health challenges.” Participants also described instances of being intimidated by having to speak in front of mental health professionals due to their past negative experiences in treatment. Participant 3, for example, said that the first time she was asked to do a presentation alongside a psychiatrist, she noticed that she felt as though she should not be there. She remembered noticing at the time, “even in my own mind, I have this kind of power imbalance thought, this paternalism thing going on.” Because of this felt pressure to prove that they understood the work being done, the participants took extra time to read and prepare for each meeting. Participant 5 explained:

“People sometimes, when participating in a team of experts, researchers, make you feel, sometimes intentionally, maybe sometimes unintentionally, that you are the one intruding with less knowledge, that it’s a burden on other team members to take time to explain you issues, concepts. I don't like that. My mental health condition is not a barrier to understanding… I don’t want people to minimize my expertise and my abilities only because I was not there from the beginning and… was not familiar with the language they are using. I don't want people to make me feel that I am a burden to the team members because I lived the experience... It brings more of a burden on me because I have to read very thoroughly before the meetings so that I am not left alone in the discussion, but this is not fair. I’m doing a reasonable accommodation for myself unduly while the research members should be there to assist me.” (Participant 5)

She went on to explain that sometimes in her role as a psychosocial disability representative she will need more time because the issues being debated are not just abstract to her, but deeply personal. She gave the example of working with a committee on psychotic
experiences, and having the content and debate trigger her own “fresh memory of a psychotic episode” that involved restraints and needing a week away from the work as a result.

Despite this increased burden and the extra time needed to prepare, more than half of the participants brought up instances when they were asked to send comments or sign off on long technical documents on a very short deadline. Several participants independently referred to these practices—not involving people with psychosocial disabilities until the end of a process and asking for their support with very little time to review or make changes—as attempts at “tokenism,” and they understood it to be deliberate. Participant 7 explained: “the whole structure, in terms of the way global mental health operates, feels more like a structure of tokenism to give legitimacy to the work without the full and effective participation of persons with psychosocial disability,” adding, “they’re just getting us into the process to legitimize whatever they are doing.” Similarly, Participant 3 described being involved in a project where despite “advocating to be a part of these initiatives right from the start,” she was “dumped in somewhere along the line” as an “afterthought,” because “oh, now we realize we need some lived experience involvement.” She added that the short timelines add to the experience of tokenism because it forces her, if she participates, “to speak on behalf of all people with lived experience” without being given the time to “engage with other people’s lived experience and hear their views on this.” She added:

“That really puts you in a bind, because if you refuse to comment, then you don't get to have an influence at all and you maybe can't take out any of the more harmful pieces. But if you do participate then it sort of reinforces this pattern where you're not included until the very end and they use people with psychosocial disabilities to kind of sign off on it and say, ‘look, we were inclusive.’ So, you're kind of put in a really difficult situation then.” (Participant 3)

To this point, several participants described having the experience of feeling stuck when deciding between whether to engage in certain projects or to remove themselves and
their organizations entirely. Participating risked lending a sort of legitimacy to a project they did not agree with, by giving the appearance that it included lived-experience perspectives, but it could also allow them to have some influence on removing the parts they found most dangerous. On the other hand, if they refused to participate, it could send a message that these projects need to be more inclusive from the start, but it risked allowing a project to move forward that would violate human rights standards. Participant 8 echoed the experience of tokenism saying that “in these institutionalized spaces people with psychosocial disabilities are seen only as an endorsement. They care about our testimony, not our participation in any active way that could lead to transformation.” He added, however, that “the lack of alternatives forces us to take advantage of any space that is open to make change, to transform.” When Participant 7, and the advocacy organization he worked with, decided to withdraw from projects that were not operating in compliance with the CRPD (either in their process or their proposed treatments), he found that the researchers and policymakers in the MGMH found other lived-experience and mental health advocacy groups to sign off on their work. “So, the question is then do you leave them to do that, or do you try and create a space for negotiation?” He explained that he has decided to “engage with all these actors and tell them, ‘Look, these are the bare minimums in the CRPD. We have to work around the CRPD being the standard.’” He found this strategy allowed him to have meaningful engagements to “ensure that the services respect human rights, they respect inherent dignity, they respect individual autonomy, and they are contributing to the inclusion of persons with psychosocial disabilities.” He added:

“I might not be able to achieve a hundred percent what I want in terms of full compliance with the CRPD. But the problem is that when you create a situation where it's you against us, then at the end of the day, there's much, much, more lose
because they will find other people who really are not well-grounded in the issue of human rights.” (Participant 7)

While some MGMH projects switched to different lived-experience groups rather than reform their goals or processes, others would pick representatives with different philosophies as part of a divide-and-conquer strategy that took advantage of disagreements between psychosocial disability advocates to undermine their position. In this way, the tensions among subgroups within the psychosocial disability umbrella can detract from their advocacy goals. Participant 7 gave an example, highlighting how divergence on the issue of legal capacity and forced treatment between advocates can thwart their efforts at reform in the context of the MGMH:

“For some organizations, forced treatment is okay or and for others, who look at the CRPD standard, it's not okay. So, you are going before a legislative committee and you guys are both representatives of organizations of persons with psychosocial disabilities and yet you have divergent views… then it seems to weaken your position when the movement is split on these issues, when you're in those larger meetings with grant makers or global mental health experts… it sort of takes away some of the power of your argument.” (Participant 7)

While the opportunity to collaborate on new projects with the MGMH risked tokenization, participants found that allowing professionals to collaborate on new psychosocial interventions developed by advocates outside of formal systems risked “co-option.” A few participants spoke of the risks of having alternative healing modalities, outside of the mental health system, co-opted by professionals. This came up particularly in reference to peer support groups. For instance, Participant 6 gave the example of a time she invited a psychologist to participate in a peer support program she had developed, only to find out later that he had started his own group, turned it back into an expert-patient hierarchy, and was charging people to attend. She learned from this that when she was “open and trusting of the good faith of people” and included mental health professionals, “because, I don’t know, I
thought maybe they know something,” it could result in being “co-opted.” She regarded his
decision to monetize the group as a “travesty,” saying that “especially in a country where
maybe ten percent of people could afford to pay… that’s not a solution… and that’s
dangerous.” One participant described the experience of realizing that even when MGMH
researchers have “good intentions,” they can still fail to “engage people with lived experience
in a meaningful way.” She talked about being on a major workgroup run by leaders of the
MGMH movement and thinking, “they don’t know how to involve me” and “they don’t
know, they have no tools, they have no guidelines” on how to empower “lived experience
involvement in its fullest form.”

Because of their experiences of these power dynamics, tokenization and co-option,
several participants discussed developing guidelines and best practices for the inclusion of
people with psychosocial disabilities, and made several key suggestions. First, they called on
researchers, funders and governments to work collaboratively with psychosocial disability
organizations, who could then select their own representatives to work on the project. By
selecting several advocates with diverse experiences and views relevant to the topic, the
organizations can prevent the project from “cherry-picking” representatives who they believe
will be less challenging to their aims and goals. Once engaged, they recommended that
people with psychosocial disabilities be included in all phases of the research, from the initial
design through implementation and evaluation. In addition, throughout the collaboration
reasonable accommodations should be made that maximize their ability to contribute,
including training in relevant discipline-specific jargon and knowledge, the ability to request
extra time and support, and a recognition of the importance of lived-experience perspectives
to the success of the project.
**Transforming Global Mental Health and Ending Traumatic Practices**

Participants were optimistic about the potential for full inclusion of people with psychosocial disability to transform the MGMH. Participant 5 captured the sentiment put forward by many of the participants:

“Full participation of people with lived experience will change everything from intention, from the way of doing it to the service delivery, to policy, to legislation, community awareness, to insights, everything. Because they are the end users of the services, call it policy, call it legislation, call it treatment, call it research, call it intervention modalities. They are the end users with a very personal stake in this. The more you have a personal stake in anything, the more concerned you are about the genuine outcome, the effectiveness… because it affects you personally… there is no stage that, people with lived experience should be left out in the process of research, projects, monitoring, evaluations, implementation, service delivery, policy legislation, peer support, advocacy… the more they are involved, the more we are accountable to them.” (Participant 5)

Notwithstanding the tensions and disagreements explored in the preceding themes, participants saw the psychosocial disability framework as having the potential to unite lived experience groups in working together toward certain shared goals. Multiple participants saw the diversity of experiences and perspectives among these advocates as a strength, as long as they could collectively resist being broken into competing factions. Participant 6 encouraged the adoption of the principle of mutual aid, to “work together” instead of acting as “competition,” adding: “We’re all struggling the same. We’re just being oppressed by many different aspects of the same structure… let’s help each other out.” For Participant 8, the psychosocial disability framework was essential to “generate a critical mass of people,” who are “users of these services” and “know these places from the inside,” elevate “the expertise of self-experience,” and then “shape health institutions” by “articulating and generating something different than what has been proposed by the biomedical model.” Participant 5 contested what kind of expertise was most important for improving and implementing global
mental health, saying that “you need a very, very small amount of technical knowledge to bring mental health services to the most disadvantaged people anywhere in the world.” For the more difficult and subtle questions regarding how to make sure people feel supported and how to get “the understanding of the issues and the context on the ground… you have to have the story of the lived experience.” She went on:

“The story is there, the experience is there, they know best what is best for them. But you have to be open-minded and genuinely ready for new recommendations, new ways of thinking, even if it's costly, even if it means going back to a level zero of the project… it would change a lot of things if they were really involved at each stage of any undertaking in mental health.” (Participant 5)

Participant 2 also hoped that listening and learning from the experiences and stories of people with psychosocial disabilities, “would bring, in the long term, clarity about how some treatments might seem good in theory but can be traumatic for people.” She hoped that by hearing about how practices like physical restraints and ECT, in particular, were often experienced as traumatic, medical professionals might look beyond the “textbooks that say it works” and question their practices. While some participants expressed doubts over whether the MGMH was motivated to set aside costs and timelines to listen with an open mind to their stories and recommendations, they identified ways in which the psychosocial disability framework could be leveraged politically to make important changes. As Participant 7 observed, “I could have a very nice story of my experiences in the mental health system, but it has to be grounded on some formal legal policy or framework.” Without legal and institutional pressure, things would be unlikely to change substantially.

To this point, one reason for optimism highlighted by participants was how the psychosocial disability framework positions advocates with lived experience to collaborate with large disability, human rights, and donor organizations to change mental health laws and
practices. For example, participants detailed collaborations and support from large human rights institutions such as the United Nations (UN), international disability organizations, health policy groups, the World Health Organization (WHO), large funding agencies such as USAID, and several NGOs working on healthcare or human rights globally. Participants credited the support of these institutions for creating pressure on governments to sign on to the CRPD and begin in-country reviews of their compliance with these standards. While many noted that this work with government was slow and difficult, they also celebrated significant changes to mental health laws that came out of this review process.

Several participants discussed using the CRPD to change mental health laws in their countries, as part of efforts to end traumatic practices. For example, one participant mentioned that mental health laws not amended since the colonial era were now being revisited and revised, and that compliance with the CRPD had played a large role in these debates. Due to the advocacy efforts of another participant, their local government developed a plan to “reduce institutionalization step by step” while increasing recovery-based outpatient care. While she stated that “what we’re really advocating for is tearing it [the asylum] down,” she expressed excitement about some movement on this issue. Another participant described new attention to discrimination in the workplace and legislation designed to incentivize employers to hire and retain people with disabilities (including people with psychosocial disabilities) by providing reasonable accommodations. She found that companies were finding ways around this requirement, but the creation of the law nonetheless gave her organization the ability to advocate in court for people with psychosocial disabilities who were wrongfully terminated.
Meanwhile, working in tandem with the larger disability movement, participants have collaborated with governments and international development partners to open up conversations about how to ensure that funding for new development projects is compliant with the CRPD. As these projects often involve large investments and are tied to funding designed to aid countries in meeting Sustainable Development Goals (SDGs), participants found that governments tend to be “suddenly very responsive to our human rights concerns.” Several participants discussed the WHO QualityRights initiative, seeing this work as an important step both for the inclusion of people with psychosocial disabilities in its production, and for its potential to influence governments, funders and researchers worldwide. One participant declared that the QualityRights initiative allowed him to go to his local ministry of health and say, “if the WHO can recognize that the status quo needs to change and we need to adopt standards as they are laid down in the CRPD, then I think it is important for us to have critical discussion around the convention.” Similarly, multiple participants cited the work of the UN Special Rapporteur Danius Puras, acknowledging that his efforts to promote rights-based mental health had generated new opportunities for their advocacy.

Acknowledging that “the law cannot address all issues” and that “there are things which we must address beyond the law,” participants also highlighted new approaches to research and support services opened up by the psychosocial disability framework. They described how the framework enabled them to “take a more comprehensive approach” and begin developing programs that would respond to people in distress or crisis in ways that respected their human rights. For example, one participant detailed a new initiative where, “instead of having police as the first line of intervention,” they had a counselor and peer
support workers meet with the person in distress and their family. Another participant used the CRPD to advocate for a study investigating “how peer support can contribute to supported decision making,” thus allowing for the reduced use of forced treatment. Yet another example by a third participant involved a peer-run “respite place for people that are experiencing non-ordinary states,” where people might go to recover without having to fear forced medication or restraints.

Participants also noted the importance of going beyond alternative methods for responding to acute distress, important as these are, to address “the whole of a person: psyche, body, soul, mind, environment, everything.” Participant 5, for instance, stated that “the divide between treatment and social determinants” needed to be challenged. She explained:

“I think when we say global mental health, global shouldn't only refer to geography. If you say global mental health, global should also refer to what is global in the person… For example, if you live in poverty and struggle for having a meal, even if you give me treatment for my depression, you are not treating maybe the real cause. So, each time that I am hungry, each time that my family is going through a difficult time, economically, financially, I go back to my depression. So, there shouldn't be a divide… between treatment and social determinants. Of course, the social determinant by itself should be treated also, if we consider global to be truly global.” (Participant 5)

For this reason, participants advocated for applying the psychosocial disability framework to stimulate reinvestment in local communities through the recognition of existing resources and the development of rights-based psychosocial supports. For example, one participant described a project that targeted social determinants like poverty and substance use in people with psychosocial disabilities by connecting them with employment and working to increase their engagement in the community. In line with this thinking, another participant worked to develop and adapt existing healing methods in local communities, and increase access to
these supports as an option before sending someone to mental health care. She explained that in her country, “the family may prefer to resort to some cultural remedies, spiritual remedies, traditional healing, family treatments, social supports.” Adding resources and ensuring the protection of rights through these existing supports creates services that are culturally appropriate in contexts “where spirituality is very influential and explains almost every action in society,” and has the added benefit of increased investment in the community. If the distress went “beyond what the cultural and traditional remedies could bring,” she added, “then people would bring service users to modern psychiatry.” For her, “the bottom line is, we have to make the best use of what we have on the ground, in the social fabric, so that the service user is treated and considered in the best way possible.”

Because of the attention to social determinants inherent in the psychosocial disability framework, participants reflected an overall optimism that their advocacy could lead to broader social interventions and policy changes benefiting other marginalized and oppressed groups. Participant 8 argued that people with psychosocial disabilities share a common struggle with sexual minorities and drug users, as they also “have faced a lot of discrimination, violence, exclusion,” and are “stigmatized, and most of the times pathologized, and end up in similar situations like the ones that people with psychosocial disabilities face.” He argued for an “intersectional perspective, considering discrimination as a factor that affects a major population in the world,” so that psychosocial disability advocates could make common cause with other oppressed peoples. “I believe that's the challenge,” he concluded, “to see these subjects as situations that require broad participation, social participation, plural participation to really impact the public agenda.”
The purpose of this chapter is to discuss the qualitative results in greater depth, synthesizing the findings in the context of previous research and exploring how the themes generated contribute to an understanding of the research questions outlined earlier. Table 3 provides a summary connecting the research questions to the results and analysis. An overarching goal of the present study was to investigate how the conceptualization and implementation of the psychosocial disability framework can provide a counter-discourse to the Movement for Global Mental Health (MGMH). For this reason, the themes that emerged from the experiences of the psychosocial disability advocates in this study are discussed in terms of the possibilities for subjectivity and action that are either created or foreclosed by the contrasting discourses of psychosocial disability and global mental health.

**Conceptualizing Psychosocial Disability**

The participants in this study represented diverse perspectives on what psychosocial disability meant to them and what it was like for them to adopt, at least in certain contexts, the identity of a person with a psychosocial disability. In this way, the study can contribute to the process whereby people with lived experience develop theories and models of madness and distress from a first-person perspective. Indeed, scholars in critical disability studies affiliated with the European Network of (Ex-)Users and Survivors of Psychiatry have pointed to the necessity for such self-articulated frameworks in the wake of the CRPD (Russo & Wooley, 2020). Further, Russo and Wooley (2020) have called for a conceptual model,
analogous to the social model of disability, to be developed and put forward in order to prevent the theoretical gap from being filled by the predominant psychiatric discourse when institutions attempt to implement the CRPD. At the same time, however, others have warned against replacing “one orthodoxy with another; one monolithic theory with another” (Beresford, 2015, p. 257). While a formal conceptual model of madness and mental distress has not yet been fully articulated or accepted to complement the CRPD, advocates (including the participants in this study) have adopted psychosocial disability as an identity and “lived into” an evolving conceptualization of this identity to make sense of their own experiences and work toward change. As Anderson et al. (2015) write:

“After all, activists don’t have to wait around for the ‘right’ or ‘correct’ theory–one that solves all the challenges they face–before they act to defend or advance their collective interests. Indeed, some of the most powerful learning takes place in the process of articulating the struggle against oppression or initiating social change–when people attempt to make sense of what is happening to them and to formulate a plan for action.” (p. 289)

As such, the experiences of the participants described in the results capture the concept of psychosocial disability as it was being used to effect change in different contexts.

As contexts and circumstances varied for participants, they made sense of the psychosocial disability framework in novel and sometimes contradictory ways, typically toward pragmatic ends. It is also likely that participants were at different points in their “journey,” as it was often referred to, with the psychosocial disability identity. They may, therefore, be at different stages of “conscientization,” or degree of consciousness about their location in systems of social and political oppression (Beresford, 2019). Add to this the myriad other differences in cultural context, personal history, type of advocacy, etc., and it complicates attempts at “monolithic theory.” In this way, the results speak to the advantages of an overarching umbrella framework that simultaneously reframes the debate about mental
health in important ways, while leaving room for bottom-up and personal theorizing that could be adapted to the beliefs and needs of diverse individuals and groups the world over.

**Openness to Diverse Meanings of Impairment**

The participants spoke to the importance of leaving certain questions open, particularly those of etiology and impairment, so that individuals would have the freedom to explore and come to their own narratives and frameworks to make meaning of their experience. This respect for everyone’s right to work through and make meaning of their distress is consistent with the ethic of Mad studies scholars who underscore the importance of creating spaces “where no one individual, school, institution, or local community holds authority or ownership over its definition and the directions it may take” (LeFrancois et al., 2016, p. 1). The results also highlight that the personal journey of moving through different frameworks for understanding distress was essential to participants’ experiences of finding recovery and community. Participant 6, for instance, connected being “lucky enough to find a narrative” and “a little bit of a framework” to avoiding being “tied to a bed again” and “develop[ing] a strong, strong community.”

The results also highlight how participants were conscious of not replicating the top-down power dynamics they experienced in mental health settings, where an explanation was imposed on their experience. In this way, the psychosocial disability framework exemplifies the value of *epistemic modesty* or *epistemic humility* (Cosgrove & Herrawi, 2021). Epistemic humility involves acknowledging the inherently partial and incomplete nature of any explanation, and that allowing a diversity of perspectives to flourish will reveal more about the phenomena than insisting on a singular or heterodox view (Teo, 2019). In contrast, the term *epistemic violence* has been used to describe what happens when individuals and groups
TABLE 3

Brief Overview of Results and Discussion

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Results</th>
<th>Discussion</th>
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<tbody>
<tr>
<td>How did the participants’ lived experience of mental distress and treatment shape their identity as people with psychosocial disabilities engaged in advocacy?</td>
<td>Distress/madness met with biomedical model and treatment that was experienced as limited and sometimes harmful.</td>
<td>Encounters with the biomedical model reveal the epistemic violence of imposing a top-down reductive interpretation on experiences of mental distress/madness.</td>
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<td>Participants sought recovery through psychosocial supports and began engaging in mental health advocacy as a person with lived experience.</td>
<td>Advocates who identified as people with psychosocial disabilities deliberately avoided top-down frameworks, instead employing epistemic humility and making room for explanatory pluralism within the definition of psychosocial disability.</td>
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<td>The emergence of the CRPD was experienced as opening up new ways of thinking about their own identities and presenting opportunities for advocacy.</td>
<td>The incorporation of the social model of disability facilitated an understanding of distress that connects the individual to their socio-cultural word, consistent with neuroecosocial approaches.</td>
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<td></td>
<td>Participants began to see psychosocial disability as an umbrella term for a diverse range of people with lived experience with different backgrounds and perspectives.</td>
<td>Identifying as a person with a psychosocial disability led to new understanding of self as rights-holder that challenged existing scientific, legal and institutional practices.</td>
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<td><strong>See themes I.1, I.2, I.3, and II.1 in Table 1</strong></td>
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<td>How does the psychosocial disability framework shift how advocates make meaning of their activism in the context of the Movement for Global Mental Health (MGMH)?</td>
<td>The diverse identities and perspectives of different advocates with psychosocial disabilities highlighted differences over certain key issues including impairment and forced treatment.</td>
<td>Tensions between people with psychosocial disabilities over how (and whether) to engage with the MGMH reflect different standpoints and political strategies.</td>
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<td>The conception of psychosocial disability adopted by participants shifted the focus of advocacy efforts toward promoting rights and addressing social determinants.</td>
<td>The integration of human rights into the conception of psychosocial disability was opposed by powerful psychiatric and pharmaceutical organizations but is reflected in recent developments from the UN and WHO.</td>
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<td>Participants were afforded greater influence on mental health research and policy under the psychosocial disability umbrella.</td>
<td>Support for rights-based mental health can be leveraged by people with psychosocial disabilities to push for inclusion in all facets of mental health research and policy.</td>
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<td><strong>See themes II.1, II.2, II.3, II.4 and III.1 in Table 1</strong></td>
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<td>What are the advantages of using a psychosocial disability framework when engaging in advocacy related to the Movement for Global Mental Health (MGMH) and what barriers do these advocates face?</td>
<td>Participants had increased access to engage with the MGMH but faced several barriers to full inclusion.</td>
<td>The conception of psychosocial disability brings attention to the interpersonal and contextual dynamics that can prevent or enable full and effective participation.</td>
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<td>Participants experienced the power dynamics involved in engaging with the MGMH as “tokenizing” and reflective of colonial histories.</td>
<td>The psychosocial disability framework has the potential to create a paradigm shift in the MGMH, drawing attention to the interaction between mental distress, social determinants, and barriers to rights.</td>
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<td>The potential to transform the MGMH beyond a narrow biomedical approach and end traumatic practices encouraged participants to push for full inclusion.</td>
<td>Psychosocial disability reimagines rights-based mental health care as one among many supports including traditional healers, family-focused recovery, community inclusion, rights protection, and peer support.</td>
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<td><strong>See themes III.1, III.2, and III.3 in Table 1</strong></td>
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with more power speak about those with less power, reducing their experiences to render them legible and digestible to those with more power (Spivak, 1988).

While Spivak developed the concept to discuss the dynamics between the Global North and Global South, the concept has been applied to the phenomenon of doctors and mental health professionals dismissing the testimony and interpretation of mental health service-users as unreliable and re-narrativizing their experience in terms of psychiatric diagnosis (Crichton et al., 2017). In the case of the participants in this study, both applications of the term apply. Indeed, Participant 8 noted a “certain accord” among psychosocial disability advocates not to question one another’s choices about the type of treatment or support they sought out and contrasted this with how, in the mental health system, certain treatments are presented as “the only option available or imposed on a person.” Meanwhile, Participant 6 warned that if psychosocial disability advocates “try to impose our views on each other, we are recreating the problem ourselves of oppressive power dynamics and hierarchies,” and went on to connect the MGMH to colonialism and white supremacy.

The epistemic humility displayed by the participants with respect to the issue of impairment makes room for explanations of madness and mental distress that begin from different perspectives and prioritize different levels of experience. In this sense, the lack of a firm consensus on impairment may be a feature, rather than a bug, of the psychosocial disability framework. Indeed, this may make it compatible with versions of both explanatory pluralism and standpoint theory. Explanatory pluralism, broadly, refers to the notion that instead of attempting to reduce experience to either biological, psychological, or social...
explanations, different levels of explanation can be employed pragmatically to answer different questions (Van Bouwel, 2014). A form of explanatory pluralism was invoked by Participant 3, when she discussed her reason for leaving room for certain medical explanations despite her recognition that there are also personal and social causes of impairment. Standpoint theory, arising out of feminist philosophy, provides a conceptual tool for examining how people actively construct divergent ways of thinking and knowing based on their social location, (Ruck et al., 2019). This theory resonates with the repeated observation by participants that advocates with different philosophies had come to their views through reflection on their own experiences amidst different social and cultural circumstances.

One of the risks of uniting diverse groups of people under an umbrella term such as psychosocial disability is that it can appear to universalize what is a contextually contingent experience, and conflate varied conceptual positions. For example, Voronka (2016) described the political risks that emerge when “people with lived experience” is used “as a form of strategic essentialism to unify our divergent ways of making meaning of our experiences to enact political gains” (p. 190). For Voronka, strategic essentialism involves taking up a universal identity and acting as if that identity were a stable entity for the sake of achieving certain socio-political goals. One risk of strategic essentialism is the way it can obstruct important socially produced differences in the seemingly homogenous identity of “lived experience,” i.e. racism, sexism, etc., eclipsing how people with lived experience are differently positioned. While the participants in this study did actively construct the psychosocial disability identity as a “political statement” with strategic value, an explicit
appreciation of explanatory pluralism and standpoint theory concerning different approaches to impairment can mitigate against the risk of flattening ideological differences.

**Humanizing Disability, Diversifying the Human**

While the psychosocial disability framework may be open to different conceptualizations of the etiology of impairment, it is committed to the social model of disability and the incorporation of people with psychosocial disabilities into the spectrum of human diversity. All participants put forward a description in line with the social model of disability; namely, the perceived impairment of the individual (madness/diversity/difference) is met with a social reaction of oppression and barriers to a full and meaningful life are created, leading to disability.

Putting aside different conceptualizations of impairment, the participants put forward an interpretation of the resulting difference as, “part of the nature of human beings… part of the diversity” (Participant 4). An analogy was drawn to physical disabilities in this regard, with Participant 2 saying, “the same way that when you wound your arm, you need support to heal, the same way the mind needs support to heal.” Here, a tension arises between the framing of impairment as a “natural” phenomenon or as arising out of inequality and social ills. As noted in the results, this analogy to physical disability alludes to the possibility of recovery and, indeed, several participants saw their particular forms of distress/madness/mental disorders as potentially temporary. The possibility of recovery can be controversial, with some criticizing the biomedical model for being fatalistic and others criticizing the implication that there is an impairment that needs to change (Morrow, 2013). The psychosocial disability framework raised an additional issue concerning recovery, as Participant 1 pointed out when he asked whether the removal of social barriers would mean
that someone could no longer identify as a person with a psychosocial disability. His question points to the conceptual and political risks involved in incorporating recovery into this framework, as it may be used to suggest that once someone “gets better” social supports and protections can be withdrawn.

This framing of impairment as a normal or natural way of being human, rather than fundamentally “other” in some way, resonates with a core principle of the neurodiversity movement; namely, that such conditions “embody human diversity rather than representing pathology or deficiency” (Beresford, 2015, p. 254). This resonance has also been noted by Graby (2015) who argues that neurodiversity has the potential “to bridge conceptual gaps between the disabled people’s and survivor movements—which as the sticking point between them over the concept of ‘impairment’” (p. 241). Neurodiversity, developed initially by people who identify as Autistic or with the autism label, is consistent with the social model and psychosocial disability framework in that it sees disability as arising from social oppression in response to minority traits. Some proponents have dealt with the issue of impairment differently, however, viewing it as a difference best explained in terms of neurobiology and affirming diagnoses like “ADHD” as “real” entities that should be celebrated and accommodated. While those in this study who continued to identify with a psychiatric diagnosis spoke about it in similarly biological and universalizing terms, most of the participants eschewed such diagnostic categories. Meanwhile, recent theorizing on neurodiversity has developed alternative conceptualizations of impairment that do not reify diagnostic categories and define function and dysfunction relationally rather than as intrinsic to the person (see e.g., Chapman, 2021). In this vein, some scholars of psychosocial disability have proposed an alliance between the Hearing Voices Movement, led by people who hear
voices and are outside of the mental health system, and the neurodiversity movement (Hart, 2020). The conception of “psychosocial diversity” was also embraced by the Lima Declaration, discussed earlier, as an umbrella term for people with lived experience (Redesfera, 2018).

**Out of the Biomedical Model and Into the World**

Perhaps the most important conceptual shift marked by the psychosocial disability framework is the move away from narrow biomedical explanations and treatments of madness and mental distress toward more social approaches. While participants in this study had different experiences and levels of comfort with psychiatric medications and treatment, all described the prevailing model in mental health as overtly biomedical and limited. By this they meant the tendency to view people in distress as deficient and needing to be fixed, typically through the prescription of medication, with little attention given to the material, psychological, and relational realities of their lives (see e.g., the “Mental distress meets the biomedical model” theme). In this description they echo the observations of several prominent psychiatrists who have decried the field’s myopic focus on neurobiological research and pharmaceutical treatments. A recent example, in the prominent *New England Journal of Medicine*, described “biologic psychiatry” as “plagued by over-prescription of psychiatric medication” and a “falsely deterministic formulation of mental illness and its treatment,” leading the authors to call for a “fundamental rethinking of psychiatric knowledge creation and training” (Gardner & Kleinman, 2019, p. 381). Prominent historians of the field have recently drawn attention to the failure of such an approach to improve the lives of service-users, connecting the current paradigm to austerity politics and neoliberalism in the Global North (Harrington, 2019; Scull, 2021).
Responses to this call for a fundamental rethinking center around a new paradigm that would shift the focus away from brain disorders, toward the cultural and social determinants of global mental health (see e.g., Di Nicola, 2019). The participants in this study saw the psychosocial disability framework as particularly useful for drawing attention to this need to take social approaches more seriously. This is consistent with past qualitative studies by and with service-users in the Global North, who observed that a biomedical model based on pathology was dominant in their treatment and largely unhelpful, while social approaches were helpful but underutilized (Beresford et al., 2010). Similarly, Russo and Wooley (2020) argue that new conceptual models of madness and mental distress developed by those with firsthand knowledge should include a focus on how societal structures lead to disability. Acknowledging that biomedical and individualistic conceptions of mental distress inherent in the psy-disciplines developed out of the politics and worldviews of the Global North, some have suggested that learning from the Global South is necessary for developing broader notions of health (Di Nicola, 2020). Accordingly, the present study highlights how psychosocial disability advocates in the Global South are reimagining madness and mental distress in a way that disrupts the conceptual divide between the individual and social world.

**Breaking Crude Binaries: Mind-Body, Self-World, Science-Rights**

The results of this study illustrate how psychosocial disability advocates conceptualize madness and mental distress in ways that challenge binaries common to the psy-disciplines. For Participant 5, thinking through the lens of psychosocial disability meant considering “what is global in the person,” including, “the whole of a person: psyche, body, soul, mind, environment, everything.” She also noted how this conceptualization challenged “the divide between treatment and social determinants.” As noted previously, debates about
approaches to mental health have often broken down into the question of whether to focus on access to treatment or initiatives to address social determinants. The psychosocial disability framework, as described by participants, does not fall on one or the other side of this debate. Instead, participants regularly underscored the centrality of their personal histories, cultures, and local contexts in shaping experiences of distress and which supports they felt they could benefit from. Their conceptualizations are consistent with developments in cultural and social psychiatry to rethink the determinants of global mental health. For Kirmayer (2019), an “ecosocial approach” considers how our social and cultural worlds “constitute brain and mind across development and are therefore central to processes of psychopathology and healing” (p. 31). Similarly, an integrative “neuroecosocial” approach forwarded by medical sociologists suggests that our social and cultural meaning-making systems shape our physical environments and influence our neurobiological development (Rose et al., 2021).

A nuanced conceptualization of the reciprocal and multilevel interactions between social, psychological, and biological processes also breaks down the mind-body split. In the psy-disciplines, this refers to the tendency to view physiological and psychological processes as separate; it is particularly evident in discussion of psychosomatic conditions, where symptoms with a known physical cause are seen to be outside of our control while those with a supposed psychological origin are viewed as our responsibility (Kirmayer & Gómez-Carrillo, 2019). Participant 7’s description of his psychosomatic pain symptoms belies this dichotomy. He came to understand the emergence of his pain as being inextricably related to the existential shock of his father’s death, the cultural expectations he felt to take on the “burden and struggle” of leading his family, as well as the material realities of poverty. He found that being able to talk through his circumstances in relationship to other peers and
finding supportive employment allowed him to return to meaningful participation in his life and community. His understanding of his own experience reflects how the psychosocial disability framework can disrupt the conceptual limits of predominant models and make room for integrative approaches.

The experiences of the participants also troubled the boundary between objective science and subjective values through the integration of science and human rights. The experience of coming to see themselves as rights-holders, for example, shifted their sense of self and reoriented them toward seeking out supports and advocating for others. In this way, the psychosocial disability framework makes human rights central to both the methods and goals of advocates. The idea that public health approaches should be guided by explicit values rather than “scientific evidence” challenges typical assumptions about the primacy of objectivity, universalism, and rationalism in the psy-disciplines (Cooper, 2015). These assumptions are apparent in the experience relayed by Participant 8, in which his attempt to introduce his former psychiatrist to the CRPD led the psychiatrist to respond that he would not trust anything without a bibliography. The participant discussed feeling as though this was a dismissal, suggesting that the psychiatrist was only interested in objective scientific evidence whether it conformed with subjective values or not.

Psychosocial Disability and the Politics of Mental Health Advocacy

In addition to these binaries mentioned above, the focus on human rights as an essential component of the psychosocial disability framework challenges the boundary between treatment and recovery on one hand, and activism and social change on the other. For participants, this necessitated a shift in their advocacy beyond increasing access to treatment. At times this generated new tensions, but also new opportunities for alliances. The
results bring attention to how the larger landscape of mental health advocacy by people with lived experience was profoundly altered by the emergence of the CRPD and development of organizations for people with psychosocial disabilities.

**The CRPD-Psychiatry Tug of War**

Participants, realizing themselves as rights-holders through the CRPD, began to focus their advocacy on inclusion and social protection for people with psychosocial disabilities. Participant 7, for example, had previously worked in mental health advocacy organizations that were supported by doctors and mental health professionals since they mostly worked to increase access to medication and reduce stigma. However, once he began organizing under the psychosocial disability umbrella, which positioned him to challenge laws and psychiatric practices, he encountered opposition from “mental health professionals that were not willing to adopt the paradigm shift.”

This tension or “tug of war,” with proponents of the CRPD and rights-based approaches on one side and entrenched psychiatric and pharmaceutical interests on the other, also played out through public statements and in medical journals. For example, the *Australian & New Zealand Journal of Psychiatry*, featured a point/counterpoint between researchers who supported the rights-based focus in mental health policy and practice, including Gill (2018) and Cosgrove and Jureidini (2019), and those who dismissed the approach as “anti-psychiatry” (see e.g., Dharmawardene & Menkes, 2018). In addition, when a special issue of the journal *World Psychiatry* featured several articles calling for the CRPD to be amended, particularly to preserve forced treatment (see e.g., Applebaum, 2019), six organizations of people with psychosocial disabilities issued an open letter in response. In the open letter, the signatories–European Network of (Ex-)Users and Survivors of Psychiatry
(ENUSP), Absolute Prohibition Campaign, Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP), Red Esfera Latinoamericana de la Diversidad Psicosocial, TCI Asia Pacific, and World Network of Users and Survivors of Psychiatry (WNUSP)–declared that the paradigm shift underway, due to the social model emerging out of the CRPD, meant diminishing the social power of psychiatry:

“Based on a social model of disability, the UN CRPD and the CRPD Committee’s guidance offer us an important prospect to shift away from the biomedical paradigm when approaching madness and distress and explore not only dignified but also socially responsible and good-quality responses to human crises. This requires the relinquishment of power by the psychiatric profession and a re-definition of psychiatry’s role in society. At times of such a significant historical turn, rather than admit its many failures and join efforts to collaboratively develop different and better responses, the WPA has chosen to expand its ‘expertise’ into the field of lawmaking in order to ‘save the CRPD from itself’” (ENUSP, 2019, p.5).

A year after the open letter, survivor-researchers expanded on their position, arguing that the CRPD could not be integrated with psychiatry: “In our view, the CRPD came about not as a demand to change psychiatry but rather as a clear call to change policies, practices, and mindsets that create psychiatry” (Russo & Wooley, 2020, p. 155). Due to the inherent power imbalances at play, Russo and Wooley argue that survivor-advocates cannot join alliances or work toward change with psychiatrists. To their point, the framing of “experts and patients” inherent in psychiatric discourse can serve to undermine the rights of service-users. An analysis of the 2007 Mental Health Act in the UK, for instance, found that experts and doctors were seen as trustworthy while patients were seen as dangerous and non-compliant, severely limiting their ability to have their testimony heard and believed (Kent et al., 2020).

The results also attest to the different ways that psychosocial disability advocates experience the power of psychiatry and other mental health professionals, particularly in terms of the connection between psychiatry and the lobbying power of the pharmaceutical
industry. Psychosocial disability advocates were at a distinct disadvantage when it came to influencing governmental policies when they were up against the money, networks, and influence of psychiatry and the pharmaceutical industry. For this reason, researchers have argued that a robust rights-based approach to mental health necessitates confronting institutional corruption within psychiatry and the commercialization of psychiatric science by the pharmaceutical industry (Cosgrove & Shaughnessy, 2020).

This “tug of war” led to participants feeling as if they were “walking a tightrope” between lived experience advocates and the MGMH. The decision whether to participate in some of these projects was fraught, as described in the results, with advocates aware of the risks of not attempting reforms. At the same time, they found that tensions between different advocates with lived experience could be exploited to maintain the status quo through tokenization and co-option. Two examples discussed in the results are the tendency to search for “token” representatives that may be more agreeable on certain issues, or to play advocates with different positions on key issues off against one another to undermine their authority. Histories of “consumer activism” in the U.S. reveal similar dynamics, whereby advocacy groups are compromised by pharmaceutical industry influence and ultimately alter their goals and priorities (Batt et al., 2020). This history suggests that psychosocial disability advocates may encounter industry-funded psychosocial disability organizations that have been manipulated to serve the interests of industry.

New Alliances, Rights-Based Approaches, Political Strategies

Psychosocial disability advocates, due to their connections with both disability justice and human rights frameworks, received support from powerful international and mainstream organizations in a way that was unprecedented for lived experience activists. The results
detail how participants reported collaboration and support with several large organizations, institutions and funders, including the UN Special Rapporteur Dainius Pūras and the WHO QualityRights initiative.

Pūras served as UN Special Rapporteur for the Office of the United Nations High Commissioner for Human Rights (OHCHR) from 2014-2020, whose mandate is the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. During his tenure, he issued several statements and reports promoting a paradigm shift toward a rights-based approach to mental health and away from a biomedical model. In line with the CRPD and the psychosocial disability framework, Pūras called on states, academic institutions, and other stakeholders to develop frameworks for the meaningful inclusion and participation of people with lived experience in the design, implementation, delivery and evaluation of mental health services, systems, and policies (Pūras, 2017). Participants credited the pressure this placed on governments and other institutions for kickstarting processes that led to changes to mental health laws and MGMH projects in their own countries. In his final report, Pūras specifically detailed the need to fundamentally transform the MGMH away from a reductionistic biomedical approach toward locally adapted and culturally attuned practices that ensure human rights and prioritize social integration, connection, participation, and empowerment (Pūras, 2020).

Multiple participants also spoke to the development of the WHO QualityRights initiative, noting the inclusion of people with psychosocial disabilities in the process as well as the potential it offered to gain the attention of governments worldwide. In June 2021, the WHO QualityRights initiative released a report on person-centered and rights-based approaches to mental health that called on governments to make human-rights central to their
approach to mental health care, and ensure access to psychosocial supports rather than simply biomedical interventions (WHO, 2021). The report also highlights twenty-two model programs internationally that provide services in accordance with human rights principles. Participants considered the WHO guidance a boon to their advocacy efforts, with one participant stating: “if the WHO can recognize that the status quo needs to change and we need to adopt standards as they are laid down in the CRPD, then I think it is important for us to have critical discussion around the convention.”

The advocates interviewed for this study all discussed how the advent of the CRPD and their own movement into the psychosocial disability arena had led to encountering a wide range of identities and philosophies among people with lived experience representing a number of different countries. Scholars of radical mental health politics have also observed and written on the resurgence of interest and debates surrounding mental health movements beginning in 2008. Cresswell and Spandler (2016) identify two overlapping yet distinct tendencies characterizing this uptick in debate in the Global North: the Mad studies tendency and the Psychopolitics tendency. They go on describe different political strategies reflected within each tendency. The Mad studies approach is opposed to psychiatric services and looks to develop voluntary forms of support outside of mental health systems, while the Psychopolitics approach is concerned with protecting access to social welfare systems and reforming services. These tensions were also noted by the advocates in this study; likewise, they differed in their tendency toward one or the other of these political strategies. Participant 6, for instance, argued for developing communal and mutual aid supports outside of the system, while Participant 1 was concerned with ensuring that people with psychosocial disabilities could continue to access disability benefits. However, participants also described
struggling internally with the question how to decide when to engage in reform and when to engage in protest. Their experiences highlight the moral complexity of these decisions and how the choice is most often driven by pragmatic considerations within a specific situational context, rather than strict ideological adherence to a particular philosophy.

**Reimagining Global Mental Health Through the Lens of Psychosocial Disability**

The experiences of the psychosocial disability advocates in their interactions with the MGMH brought to the fore contradictions between various approaches as well as barriers to meaningful engagement. The results also shed light on how global mental health research and policies might be reimagined if it were to incorporate a psychosocial disability framework, rather than a mental health framework.

The results of this study suggest that the psychosocial disability framework has the potential to create a “paradigm shift” in the MGMH. Because the framework draws attention to the interaction between the individual and social barriers, it facilitates a transition away from prioritizing access to mental health treatment and toward addressing social determinants and guaranteeing access to human rights. The evidence for the impact of these determinants is extensive in the fields of epidemiology and community mental health. Recent research, for example, finds that food insecurity predicts worse mental health outcomes across the globe (Jones, 2017), that poverty and income inequality are associated with increased suicide rates (Steelesmith et al., 2019), and that the accumulation of financial debts predicts the onset of common mental disorders (Ten Have et al., 2021). Further studies have found that both psychotherapy and psychiatric medications are often ineffective for people in poverty (Finegan et al., 2019), and that providing modest stipends can be associated with greater improvement than mental health treatment (Haushofer et al., 2020). These findings support
the contention, voiced by one of the participants, that trying to improve other social issues by treating mental health will be less effective than changing social conditions to improve mental health.

There are some indications that the MGMH is increasingly attempting to incorporate social determinants, yet is still lacking a robust conceptual model that could integrate the social into mental health. The MGMH is not monolithic, as it is composed of an ever-evolving assemblage of different institutions, universities, researchers, opinion leaders, and local collaborators. However, observers of the movement have commented on the shifts within the field in terms of how it formulates an approach to mental health and designs interventions, noting some movement from a narrow biomedically focused approach toward more complex conceptualizations (Bemme & Kirmayer, 2020). A recent analysis of the latest report from the Lancet Commission on Global Mental Health and Sustainable Development found that the report showed increased attention to social determinants, such as poverty and income inequality, but continued to conceptualize the effects of these determinants in terms of the increased presence of “mental disorders” (Cosgrove et al., 2020). As a result, the interventions offered to address these social determinants often involve working with individuals to address issues like isolation, poverty, and unemployment, without sufficient attention to the social and structural conditions that enable community inclusion and meaningful participation (Cosgrove et al., 2021).

In this vein, the results capture how people with psychosocial disabilities broaden the discussion and work on larger structural change. Participant 8 discussed work by psychosocial disability organizations to advocate for universal basic income, for example. Noting how these broadened goals might surprise those working within a mental health
framework, he wondered: “maybe a psychiatrist or a person who agrees with the bio-medical discourse, would say ‘what does universal basic income have to do with mental health?’” In another example, people with psychosocial disabilities associated with the Global Mental Health Peer Network (GMHPN) have advocated for the prioritization of universal healthcare in development (Stewart et al., 2021).

As the participants pointed out, attempting to address social issues through the lens of mental health risks obscuring the systemic drivers of these issues. Gender-based violence was discussed as a complex social and cultural issue which, when treated as a mental health issue, leaves the status quo unchallenged. This criticism is consistent with theories of psychiatrization—the sociological process of increasingly treating a diverse range of human problems as amenable to psychiatric interventions—that highlight the risks of obscuring collective and political responses to structural issues (Beeker et al., 2021). For this reason, participants underscored the importance of bringing the CRPD into discussions about economic development. While the integration of global mental health into the UN Sustainable Development Goals (SDGs) created opportunities for advocates to enter a broader range of discussions with governments, the specific framing of global mental health within the SDGs risked promoting “reductionist, economistic, individualized and psychologized responses to poverty” (Mills, 2018, p. 866). Some critics have suggested that a sole focus on increasing access to psychiatric treatment in the Global South may actually work against the intentions of the SDGs, by increasing the use of medications with heavy side effect burdens in the absence of consistent medical care and psychological supports (Lehmann, 2019). In response, people with psychosocial disabilities examined the current barriers to inclusion in development programs—including discrimination, legal obstacles, the
lack of representation of people with psychosocial disabilities in Disabled People’s Organizations (DPOs), economic exclusion, and a lack of quality pervading community mental health programs internationally (Davar et al., 2016). The advocate-scholars called on governments and international development organizations to ensure the inclusion of people with psychosocial disabilities within all development programs and the implementation of the SDGs, stating: “Now is the time for the development community to work alongside people with psychosocial disability, to change the pattern of past injustices, and prevent these being repeated in the future” (Davar et al., 2016, p. 29).

**Can Inclusion Address the Power Dynamics of Global Mental Health?**

In this study, a recurring criticism from psychosocial disability advocates was that MGMH experts did not fully understand or account for local cultures and beliefs in the Global South. For participants, the top-down imposition of beliefs about mental health as well as the interpersonal and structural power dynamics with the MGMH were reminiscent of colonialism. Participant 6, for example, explicitly referred to the MGMH as “the grandchild of the colonialism of 500 years ago” and equated the logic of the movement with white supremacism. Indeed, scholarship in anthropology, transcultural psychiatry and cross-cultural psychology have investigated the ways culture frames how we understand ourselves and make meaning of our worlds, shaping the experience of mental distress in unique and culturally specific ways (Jarvis & Kirmayer, 2021). When the MGMH imposes culturally specific understandings of mental distress on communities in the Global South, with their own evolving, distinct and diverse cultural frames of reference, it can have adverse effects that ripple throughout the society, including rampant medicalization (see e.g., the rise of bipolar disorder in Iran; Mianji & Kirmayer, 2020), increased marginalization of oppressed
groups (see e.g., the pathologization of women’s emotions in India; Davar, 2020), and the eclipsing of local ways of understanding and responding to distress (Beneduce, 2019).

To move away from psychiatry’s historical connection to maintaining social control in the interest of colonial powers (Hickling, 2020), scholars have argued that the MGMH should adopt “a ‘pluralistic view of knowledge’ that recognizes multiple voices and sources of knowledge and avoids the ‘epistemic injustice’ that occurs when the knowledge of one group is validated while others are denied legitimacy” (Bemme & Kirmayer, 2020, p. 8). Given the principles of full and effective inclusion supported by the CRPD, psychosocial disability advocates may be well positioned to contribute to this pluralistic view of knowledge, drawing upon their lived experience to bring attention to the nuances of cultural experience and contextual factors.

Case studies of the work of people with psychosocial disabilities suggest that their efforts can transform how mental health care is conceptualized in their communities. For example, the work of Bapu Trust in India has countered the current discourse of the MGMH through its attention to “local complexity (of the history of a community and its myriad networks),” which has had shifted local approaches to care toward “respect of indigenous and local forms of healing,” awareness “of alternative paradigms of care than psychiatry,” and the “promotion of non-medical and non-technical solutions” (Mills & Davar, 2016, p. 450). Participants expressed optimism that if steps were taken to empower the full and effective participation of people with psychosocial disabilities, it could transform the concepts and priorities of the MGMH. Of course, the act of including people with psychosocial disabilities does not on its own address these colonial dynamics, as participants noted how the
intersection of discrimination against people with lived experience with racism rooted in colonial histories were apparent in the course of their work with the MGMH.

The descriptions by participants of having their knowledge devalued, being seen as “not one hundred percent a human being,” internalized paternalism, and deliberate tokenization are consistent with other qualitative studies on people with lived experience participating in mental health research and policy efforts. A Dutch study on the experiences of service users engaged in the co-production of mental health research found that the relational dynamic and hierarchical contexts led service-user researchers to experience *epistemic injustice*, or the diminishment of their ways of knowing (Groot et al., 2020). Similarly, lived experience researchers have written about the systemic challenges and marginalization they face when participating in research. Reflecting on their own experience, Roennfeldt and Byrne (2020) recommend practices for creating the conditions under which meaningful co-production can emerge. This includes: cross-disciplinary partnerships and evolving means for acknowledging and addressing power imbalances; recognition of lived-experience produced research and scholarship as a body of knowledge with its own history and practices; and the cultivation of a culture where vulnerable personal experience and controversial opinions are met with openness and acceptance (Roennfeldt & Byrne, 2020).

While the full and effective inclusion of people with psychosocial disabilities is far from guaranteed, participants discussed the use of political strategies and alliances that can place pressure on the MGMH to move toward compliance with the CRPD, as well as the development of guidance on what is required for inclusive practices.
A Menu of Culturally Appropriate and Locally Developed Supports

With all of the above in mind, this study offers a glimpse at how global mental health might be restructured through the psychosocial disability framework. The participants articulated a vision of a system where people with psychosocial disabilities, including those in acute distress, would have a “menu” of possible supports that could facilitate a return to meaningful participation in community life. In this way, the psychosocial disability framework facilitates a shift away from a “one-size-fits-all approach” to addressing mental distress yet avoids an abolitionist stance toward psychiatric and medical intervention. Instead, psychiatric services are positioned as only one option among many that people could choose from for support. For example, Participant 5 advocated first offering “cultural remedies, spiritual remedies, traditional healing, family treatments, social supports” before sending someone to mental health care. A brief discussion of the other proposed supports that emerged in the interviews follows below. These suggestions are not meant to be prescriptive or exhaustive, as the structure and content will vary based on local needs and priorities of advocates. Rather, this summary is meant to illuminate how the psychosocial disability framework broadens the conception of support while also transforming existing service in compliance with human rights standards.

**Traditional Healers.** In accordance with attention to local contexts and cultures, the participants suggested that the available supports “in a spectrum of alternatives” should include local community and religious organizations and traditional healers. As mentioned previously, the MGMH has been associated with the loss of indigenous healing methods. Participants actively opposed this trend, explaining that local healers have deep knowledge of community and family life and often can intervene in ways that the mental health system
cannot. Anthropological research has documented the effectiveness of these methods cross-culturally, and identified common therapeutic components (Bantjes et al., 2017; Green & Colucci, 2020). Indeed, Western psychotherapy is itself a culturally specific healing practice that shares key features with the indigenous practices (Bedi, 2018). An important consideration in building traditional healing methods into a system of supports for people with psychosocial disability is being careful to avoid the medicalization of cultural idioms of distress (Kidron & Kirmayer, 2019).

The role of traditional healers is complicated by participants’ discussion of the potential for abuse in these practices. For instance, a participant in Central America shared the story of a woman who was burned because she was associated with witchcraft, and participants in Africa discussed instances of chaining and other abuse due to local beliefs. However, it was acknowledged that similar abuse occurs regularly in institutions and local psychiatric practices. As Beneduce (2019) argues, reviewing and incorporating human rights into traditional healing (see e.g., Read, 2019) should also be taken as an opportunity to assess harmful elements of Western psychiatry, such as “lobotomy, ECT, restraints, unnecessary use of drugs, and involuntary hospitalization” (Beneduce, 2019, p. 721).

**Family-Focused Recovery.** In line with a culturally responsive approach, the participants advocated for programs that recognize the primacy of family and communal life in many other cultures. Participants noted that families are often central to the care and support of people with psychosocial disabilities in their communities. The results highlight examples where the involvement of family is understood to be inextricable from conceptions of support and recovery, as well as cases where this encroaches upon the person’s agency. When it came to negotiating the rights of the individual vs. rights of the family to decide
what is in the best interest, participants called for a balanced perspective. These accounts are suggestive of the tension between families as essential for relational healing and families as a source of stress or trauma (see e.g., Waller et al., 2018), and point to a need to develop practices for communicating explicitly about the preferred role of family in any supports that are offered.

**Community Inclusion.** The psychosocial disability framework prioritizes inclusion as a human right, but participants also discussed involvement in community life as a necessary support and advocated for “structures that will enable the empowerment and the full and effective participation and inclusion of persons with psychosocial disabilities on an equal basis with others.” This is supported by research finding that empowering and supporting people with disabilities to engage meaningfully in community life can “enhance general medical, cognitive, and mental health and wellness” (Salzer, 2021, p. 836). In one example, a program that brought people diagnosed with psychotic disorders into contact with a volunteer partner and provided them with a financial stipend to engage in social activities led to experiencing normalcy and achieving belonging, as well as strengthened social capacities, engagement with culture, and enhanced physical health (Sheridan et al., 2018).

Community inclusion also necessitates attention to the material realities of community environments that impact wellbeing (Bratman et al., 2019). Such an emphasis within the psychosocial disability framework led participants to advocate for economic empowerment programs, education support programs, and departments on youth welfare, among others.

**Rights Protections as Intervention.** Understanding community inclusion as a human right also entails protection against discrimination by employers and social institutions. In this study, advocates worked to challenge unfair terminations at work based on
discrimination, and achieve reasonable accommodations for people with psychosocial disabilities in their places of employment. Recent ethnographic work on the implementation of rights-based employment supports in Ghana found that workplace accommodations were essential to the employment and social inclusion of those with psychosocial disabilities. In addition, discrimination and exclusion are common and disability labor laws often ignored, leaving people to turn to social protection programs to maintain independence (Read et al., 2020). For this reason, access to rights protections, legal aid, and advocacy are essential supports.

**Peer Support.** Multiple participants discussed having benefited from various forms of peer support group and advocated for the creation and recognition of peer support, both within and outside of existing mental health systems. While peer support has received increased attention within recovery-based mental health services (Mutschler et al., 2021), lived experience advocates warn that the practice is often co-opted, weakening its potential (Beresford, 2020). Participant 6 described her own experience of having a peer support group co-opted by a psychologist. Research suggests the importance of clear role definition and organizational boundaries to protect peer support workers within the system from being pressured to adopt the norms and practices of their organizational settings (Ibrahim et al., 2019). Groups led by people with lived experience also offer support outside of formal mental health settings. Hearing Voices Groups, for example, are run by people who identify as voice-hearers and aim to empower members to come to their own understanding of their voice-hearing experience while receiving support (Schaefer et al., 2021). This approach fits well within a psychosocial disability framework that, as discussed earlier, encourages a stance consistent with epistemic humility and explanatory pluralism.
**Rights-Based Mental Health.** The participants situated mental health care as a potential support for people with psychosocial disabilities to access when they choose to do so. Creating alternative supports and addressing social determinants, it was suggested, will increase options for people with psychosocial disability and make the decision to enter the mental health system less of a false choice than if there were no alternatives. The rights-based approach also seeks to transform the experience of people with psychosocial disabilities once they are within the system. Following the CRPD, service providers have attempted to develop community mental health care that respects human rights (Keet et al., 2019). As in the WHO QualityRights guidance discussed earlier, the aim is to fundamentally alter how mental health services are conceptualized and implemented. The QualityRights guidance expands upon previous scholarship on the integration of a rights-based approach into existing treatment modalities, such as Open Dialogue (von Peter et al., 2019).

While there were differences among psychosocial disability advocates on the issue of forced treatment, it was accepted that these practices can be traumatic and should be either abolished, or reduced to the point of only being used in extreme situations. To this end, rights-based approaches to crisis response are being developed based on key principles such as participation and empowerment, equality and non-discrimination, quality and diversity of care, social inclusion, autonomy, and dignity (Stastny et al., 2020). Participants also brought attention to the issue of police involvement in crisis response leading to violence and abuse, a concern relevant to mental health response in the Global North (Weine et al., 2020). The issue of “legal capacity” extends beyond crisis situations, however, and is implicated in discrimination and injustice against people with psychosocial disabilities throughout society (Tate, 2019). The participants saw the psychosocial disability framework as well positioned
to protect the human rights principles outlined in the CRPD by “putting in play this legal mechanism to fight this discrimination.”

**Recommendations**

This study brings attention to the potential of the psychosocial disability framework to disrupt and transform the MGMH. However, it also highlights the barriers that psychosocial disability advocates in the Global South face in their efforts toward “meaningful and authentic engagement.” The participants outlined several recommendations that could be put in place to improve the inclusion of people with psychosocial disabilities in the MGMH going forward:

1. Empower psychosocial disability organizations to select representatives who will be able to engage as part of a proposed collaboration. This ensures that diverse experiences and views relevant to the topic are represented.

2. Include people with psychosocial disabilities in all phases of research, from the initial design through implementation and evaluation report writing. This also includes reviews, literature reviews, commissions, and advisory groups; i.e., all processes of decision-making and strategy,

3. Ensure the provision of reasonable accommodations for people with psychosocial disabilities that maximizes their ability to contribute (e.g., training in requisite skills and knowledge, relevant information, extra time, and other supports). This includes ensuring adequate deadlines for response (i.e., not asking people for input at the last minute).

4. Explicit discussions should be held regarding how expertise of people with psychosocial disabilities will be incorporated, and power differences addressed. In
addition, collaborators should remain open to a transformation of the project based on this expertise.

These recommendations are consistent with the declarations from organizations of people with psychosocial disabilities that have drawn attention to the barriers to full inclusion (TCI Asia-Pacific, 2018; PANUSP, 2011; Redesfera, 2018). Previous studies on barriers to engaging people with psychosocial disabilities in the MGMH have also suggested that collaboration is predictably diminished when advocates are working other jobs to maintain their financial welfare, indicating the importance of setting aside adequate funding to compensate collaborators for their engagement (Murphy et al., 2021). However, payment directly from the project’s leaders can compromise their independence and interfere with their ability to challenge the status quo. For this reason, a nation’s compliance with the CRPD necessitates that its government empower and resource representative organizations serving people with lived experiences of psychosocial disabilities (Eaton et al., 2021).

In sum, the findings of this study speak to the progress people with psychosocial disabilities have made since the development of the CRPD in developing inroads into governments and institutions. However, it is important to note that people with psychosocial disabilities are still widely stigmatized, left out of social programs from which they could benefit, receiving inadequate supports, subject to traumatic practices and discrimination in healthcare, and excluded from meaningful opportunities to transform policies that impact their lives (Kleintjes et al., 2013). In response, people with psychosocial disabilities and lived experience have identified strategies for further supporting this movement, including: the recognition that people with various lived experience identities are leaders, researchers, and experts themselves (Rose et al., 2018); increased solidarity and alliances among different
groups of people with lived experience, as well as with cross-disability organizations (Beresford & Russo, 2016); and investment in a pipeline to bring people with psychosocial disabilities and lived experience into research careers and leadership positions (Jones et al., 2021).

**Strengths and Limitations**

This qualitative study was designed to elucidate the experiences of people with psychosocial disabilities as they navigated their identity, advocacy, and engagement with the Movement for Global Mental Health. To accomplish this, attention was given to methodological integrity to maximize the fidelity and utility of the analysis (Levitt et al., 2021). Fidelity refers to the intimate understanding of a topic that emerges when a researcher is immersed in the complexity of the issue at hand, has adequate data, reflexively manages their perspective throughout the study, and grounds their findings in a thorough analysis. The researcher was immersed in the major topics of study, global mental health and lived experience mental health advocacy, over the past five years–attending major conferences and publishing on global mental health, engaging with lived experience activists regularly in his own advocacy work, and working from a rights-based approach in collaboration with the UN. Additionally, the researcher spent three years on the development, implementation, and analysis of this study. Data adequacy was achieved through purposive snowball sampling, leading to the recruitment of participants who fit the study criteria and had extensive experience as people with psychosocial disabilities engaging with the MGMH. Groundedness was accomplished through advanced training in qualitative interviewing and participant feedback during analysis.
Another a strength of the study is the extensive experience of the participants. However, generalizability is also limited by the sample. The participants were all located in the Global South, where the psychosocial disability framework has received more attention from advocates. Future research examining the experiences of people with psychosocial disabilities in other geographical areas could serve to further contextualize these findings. The missing feedback from two participants on the superordinate themes is another limitation, as it leaves open the possibility that they did not find resonance with their own experiences in the summaries presented. The global pandemic that restricted travel over the past year removed the possibility of engaging with participants and their work in person, limiting the contact to video interviews. Accordingly, ethnographic and participant-observation research working within the organizations of people with psychosocial disabilities in their local context is needed.

**Summary and Conclusions**

The present study investigated how people with lived experience of mental distress and treatment come to question the mainstream discourses of the psy-disciplines, identify as people with psychosocial disabilities, and engage in activism both within and against the MGMH. The IPA study was informed by a critical-qualitative epistemology, and included eight 60–90 minute interviews with people with lived experience of mental distress and mental health treatment in the Global South who had organized their advocacy efforts under the psychosocial disability framework. In addition, all participants had familiarity with the Movement for Global Mental Health and the majority had extensive experience engaging directly with major players in the MGMH.
Through the analysis, three superordinate themes emerged: *Journeying Through Different Frameworks to Psychosocial Disability Identity, Under the Psychosocial Disability Umbrella: (Re)negotiating Identities, Advocacy Goals, and Tensions, and Walking the Tightrope During Tug of War: Global Mental Health, Barriers to Inclusion, and Transformational Potential*. The results provide novel insights into how the psychosocial disability framework, as it is lived by those who have adopted it, contributes to debates on how to conceptualize madness/distress. The lived experiences of psychosocial disability advocates, as described in these results, also shed light on how psychosocial disability has emerged as an umbrella term for mental health activists with lived experience, altering the landscape of mental health advocacy. Finally, the perspectives of the participants in this study on their engagement with the MGMH speak to how global mental health research and policies would be fundamentally transformed toward a rights-based approach by a thorough integration of the psychosocial disability framework.
APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE

Name: __________________________ Age: ____________

Race: __________________________ Ethnicity: __________________________

Gender Identity:
- Cisgender Woman
- Cisgender Man
- Transgender Woman
- Transgender Man
- Gender Nonconforming
- Other: ________________

Sexual Orientation:
- Heterosexual
- Gay
- Lesbian
- Bisexual
- Queer
- Other: ____________________

Country of Residence: _____________________________________________________

Country of Birth: ____________________________________________________________

Years involved in psychosocial disability advocacy: __________________________
APPENDIX B
INTERVIEW QUESTIONS

1) What has been your experience with formal or institutionalized mental health services?
   a. Possible prompt: Have you sought out or utilized alternative/traditional/indigenous forms of healing?

2) Has the way that you understood your experience of distress changed over time? If so, how so?
   a. Possible Prompt: Are there any language/frameworks that you found helpful for making sense of your experience at different times?
   b. In what ways, if any, do you find the use of DSM/ICD diagnoses or symptom-based language helpful?
   c. In what ways, if any, do you find the use of DSM diagnoses or symptom-based language unhelpful?

3) How did you first encounter the psychosocial disability framework and how did it impact you?

4) In your experience, how does the psychosocial disability framework aid you in making sense of your experiences?
   a. Possible Prompt: How has this framework been helpful? What parts of your experience do not fit this framework?

5) How did you come to get involved with psychosocial disability advocacy?
   a. Possible Prompt: What do you see as the primary mission of this advocacy work?

6) How does your lived experience of madness/mental distress and treatment shape your involvement in psychosocial disability advocacy?

7) How did you become aware of the Movement for Global Mental Health (MGMH)?

8) In what ways has your advocacy work intersected with the MGMH?
   a. Possible Prompt: What is an example of a way in which you have engaged with the MGMH?

9) What has been your experience of the MGMH?
   a. Possible Prompt: What do you find helpful about the MGMH? What do you find unhelpful about the MGMH?
   b. In what ways do you see the aims and methods of the MGMH as consistent with your advocacy? In what ways are the inconsistent?

10) In your experience, have global mental health efforts been inclusive of people with psychosocial disabilities?

11) What are the advantages and disadvantages of using a psychosocial disability framework to confront and reform the Movement for Global Mental Health (MGMH)?

Procedural Integrity Questions:

12) Is there anything else you would like to add, or that we did not discuss?

13) Was there anything that made it difficult to answer questions openly?

14) Do you have any recommendations for future interviews?
REFERENCES


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