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# Disrupting Epistemic Injustice: Implications for Lived-Experience Accounts of Mental Illness in Social Work Education

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**Disrupting Epistemic Injustice: Implications for Lived-Experience Accounts of Mental  
Illness in Social Work Education**

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An undergraduate Honors thesis submitted in partial fulfillment of the requirements for the

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## Introduction

While the stigma of mental illness has been studied for decades, little has been found in terms of effective interventions on this type of stigma. Researchers of the stigma of mental illness say that one promising intervention would consist of taking into account personal narratives of people with mental illness in order to better grasp the complex ways in which they perceive their experiences. Often, these stories are excluded from the educational process for people working with this population (social workers, occupational therapists, psychologists, etc.), because dominant discourse often revolves around diagnoses according to the DSM-5. The inclusion of these personal narratives of lived-experience with mental illness in the education of social workers could act as a resolution to mental illness stigma and work to deconstruct barriers to opportunities, like housing or employment, for this population.

As a social worker who is preparing to work with people with mental illness and co-occurring conditions, I want to ensure that my future clients are empowered to tell their own stories and choose their own paths to recovery as it relates to their treatment. I aspire to work collaboratively with my clients, to break down the power dynamic between myself and the people I am working with by allowing them to decide their direction in care, and to practice in a way that demonstrates to them that their autonomy matters. Most importantly, my practice with people with mental illness will work to deconstruct essentialism, or an antithesis to the idea that ‘bodies and lives are not fixed or natural’ (Thorneycroft 2020), and take into account the ways in which the social, political, and cultural contexts of each client influence their experiences.

In this thesis, I explore mechanisms of mental illness stigma and both known and suggested interventions. I introduce a Mad studies framework, a radical movement that works to emphasize the subjective narratives of people with mental illness, which stemmed from the work

of various ‘mad’ movements of the 1960s and 70s. I also discuss *sanism*, the oppression based on one’s mental illness and its invisibility in intersectionality discourse. I analyze the current Masters of Social Work curriculum at PSU in the 2022-2023 school year to find out if these concepts exist in the foundational syllabi for students, and I interview course leads in the MSW program to get a feel for their familiarity with Mad studies or sanism. I propose that the introduction of these concepts, and subsequently, the inclusion of lived-experience accounts of mental illness in the core curriculum of the MSW program, can lead to the dissolution of mental illness stigma among social workers. I will offer suggestions on literature for MSW instructors, implications for practice, and will offer implications for future research.

### ***Research Problem***

Contemporary interventions with mental illness stigma have been largely unsuccessful in bridging the gap between empathy and willingness to be in proximity to people with mental illness, among the people that stigmatize them (Fox et al 2018). In the context of this thesis, mental illness will be defined as ‘disorders of the mind,’ particularly conditions that change the ways in which we ‘think, feel, and behave,’ (Insel 2022). The stigmatization of people with mental illness can create long-term, even life-long barriers in their provision of social or structural supports, such as housing, employment, and education, often based on just their diagnosis alone (Brewis et al 2019). Various methods to reduce this form of stigma have been conducted and measured, including increasing awareness among practitioners in the medical field, stigma tracking, and the connection of evidence to policy, though few have moved the needle in any significant way (Brewis et al 2019).

In addition to the aforementioned interventions that have been employed over the years, stigma researchers suggest more community-level engagement among those stigmatized as a

means to normalizing their voices and experiences among the public, and most importantly, among the people that are responsible for providing them with care (Newman 2019).

Social workers provide crucial care and treatment to people with mental illness. The introduction of a Mad studies framework and sanism as a largely invisible oppressive structure, within schools of social work in the United States, could bridge this gap and effectively reduce mental illness stigma on a wider scale. Evidence of the efficacy of a Mad studies model in practice among service providers has been recorded by social workers assisting this population in the field, both in understanding their clients' experiences and oppressions, and in learning to switch their focus from "changing" individuals with mental illness to working collaboratively with them on their care plans (MacPhee 2022).

Social workers and other professionals working directly with people experiencing mental illness often are not exposed to the knowledges produced by people with mental illness and their complex spectrum of experiences, because their voices are often discredited in knowledge production by dominant hegemonic structures like academia and other institutions (LeBlanc 2016). If the perspectives of people with mental illness were credited and used in the production of knowledge, service providers could better understand the myriad experiences and needs of people with mental illness. Social workers, psychotherapists, occupational therapists, and other professionals in the mental health field could be less confined to unquestionably provide treatment and care according to the symptom-dependent DSM-5 and psychiatric assessments, which are commonly considered to be objective tools of measurement.

Social work has historically used a biomedical model to understand experiences of mental illness. This is a reductionist approach to mental illness that credits medical professionals as the knowledgeable experts with respect to client experiences (Menziés, LeFrancios, and

Reaume 2019). Mad studies works to disrupt the medical model, which often leads to the essentialism and pathologization of mental illnesses (Newman 2019). The medical model tends to label a person with mental illness as ‘less than,’ and the permanency of this label is implied, following the individual around in their processes in employment, housing, treatment, and other structural supports they seek (Thorneycroft 2020). Among social workers, a better understanding of Mad studies, a radical anti-psychiatry, anti-medical model framework that uses the voices of people experiencing mental illness, and of sanism, a form of discrimination and systemic oppression based on mental illness, can deepen the service provider’s knowledge of clients’ experiences with mental illness, and inform client-directed treatment to empower the client to have agency in their provision of social services.

Treatment and care should be collaborative, and based on the empowerment and direction of the person with lived-experience of mental illness, which requires the willingness of the service provider to actively take into account the very unique circumstances of each person they are caring for, and allow the client to be the expert in their own care. In this context, the term ‘lived-experience,’ will be used to refer to subjective accounts of mental illness, rather than objective definitions of such conditions (Newman 2019). Knowledge of Mad studies frameworks and sanism could effectively create a better relationship between service provider and client, as well as keep providers from adhering to dominant ideas of what experiences of mental illness look like according to the DSM-5 and psychiatric care that so often lack nuance or input from the person requiring care. This knowledge among service providers could weaken the adherence of negative labels their clients may feel confined to and offer them the freedom of negative self-perceptions they may hold onto as a result.

Social workers, particularly Masters of Social Work (MSW) graduates and PhD holders, make up the highest percentage of The Mental Health Workforce in the United States. Out of nearly 700,000 professionals in the mental health fields, about 240,000 of these are social workers (Insel 2022). This goes to show the great responsibility that social workers hold in ensuring their patients experiencing mental illness are receiving the most effective and compassionate care that takes into account their entire person (Insel 2022). My study aims to uncover whether the core concentration of the MSW program at a mid-sized urban university in the Pacific Northwest includes research centered on the lived experiences of people with mental illness, as well as offers evidence as to why an introduction of the Mad studies model among this group of students is crucial for their care for people with mental illness. This study proposes that knowledge of this concept can reduce the persistent mental illness stigma in contemporary culture.

### ***Professional and Personal Significance***

I want to work in the field of mental health, and I hope to provide the best care possible for the people I am working with, but also to shed light on the largely invisible issue of oppression caused by a person's mental illness or its subsequent manifestations.

People with lived experience of mental illness are often dismissed in their provision of resources or care based on fear, confusion, or disdain from the public and even from the people meant to care for them, leaving the person with mental illness with a lack of access to basic materials they need for survival (housing, employment, mental health care, physical health care, child care, etc.) (Thornycroft 2020). A better understanding of the personal, unique perspectives of persons experiencing mental illness could be significant in relieving them of these barriers, and open up more opportunities for them to live full, comfortable lives.

As someone who has personal experience with mental illness, I understand the frustration and hopelessness that stems from service providers' neglect to hear my own story, or to listen to my own desires and needs as a human being, as they often inherently claim to have more knowledge about my challenges than I did myself based on their educational attainment. I hope my clients will feel safe confiding in me with full confidence, and know that they are in a space in which they can be experts in the navigation of their own care, and subsequently, their futures.

### ***Ethical Principles***

Social workers have a weighty responsibility of upholding ethical principles in their research and practice, and ethical codes that exist to guide them are updated regularly in order to shift with the social, economic, and cultural climates in which they practice. The National Association of Social Work (NASW) Code of Ethics highlights a value in the “dignity and worth of the person” (NASW 2023), and I believe that in order to best support the dignity and worth of clients with experience with mental illness, it is a social worker's responsibility to allow them to tell their own story, have autonomy in their services, and be able to write their own journey to care and possible recovery.

The NASW Code of Ethics also centers the value of Social Justice (NASW 2023). Social workers act as agents of change in their client's lives, disrupting dynamics of oppression. We can do this more effectively by understanding that individuals with mental illness are systematically discriminated against based on their diagnosis, and it is up to us to work to deconstruct these barriers and advocate for the opportunities, inclusion, and humanity for people with mental illness (NASW 2023).

### ***Trauma-Informed Care***



Services meant to exist for the betterment of a person's life or circumstances, like medical services or social service spaces, can be retraumatizing for the person seeking these services (SAMHSA 2014). This retraumatization can occur when the services are coercive or otherwise infringe on the rights of the individual or group of people. Social workers must inform their practice with a trauma-informed approach in order to preserve the dignity and empowerment of the clients they serve. According to SAMHSA, social workers and other practitioners can guide their practice using the "Four Rs." In their e-book, SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach, they condense this process into the following paragraph:

"A program, organization, or system that is trauma-informed *realizes* the widespread impact of trauma and understands potential paths for recovery; *recognizes* the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and *responds* by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively *resist re-traumatization,*" (SAMHSA 2014).

Social workers can apply the "Four Rs" to practice in this context by realizing the ways in which the individual has experienced trauma in their lives, whether that trauma was in relation to their mental illness or not, and which paths to recovery may not be appropriate based on those experiences. Social workers and other professionals should be knowledgeable about symptoms of trauma and continue to learn about trauma and how it manifests in the lives of the people with whom they're working. Their practice should be responsive to this knowledge of their clients' various traumas and effects, and they should always work to resist retraumatization (SAMHSA

2014). Being trauma-informed in the field of mental health includes taking into account your clients' personal traumas, and the trauma they may have experienced socially or systematically based on their mental illness. As a practitioner of care, it is important to remember that clients may have experienced trauma from past practitioners by way of coercion or discrimination, so they may initially be resistant. Practicing in a way that is patient-directed first and foremost can create a space for clients that can actively resist re-traumatization (SAMHSA 2014).

## **Literature Review**

### **Stigma of Mental Illness**

This section will introduce a brief history of mental illness stigma in North America, and introduce a framework that navigates through the many ways in which people are harmed by this form of stigma. Next, structural consequences related to discrimination based on mental illness are discussed. Finally, possible interventions are explored.

### ***History of Mental Illness Stigma Research***

The earliest research on the stigma of people with mental illness is often credited to 1960's sociologist Erving Goffman, although it has been said other seminal work may have been conducted as early as the 1940s (Pescosolico 2013). Goffman's work included analyzing relationships between patients and staff in asylums, where he observed that the staff often viewed the patients as "untrustworthy" and "weak," and otherwise morally deficient (Pescosolido 2013). His future research expanded to include entire populations of people with mental illness, including those outside of asylums, and he defined this form of stigma as one that "marks" individuals and groups of people as "tainted and discounted." In Goffman's words, stigma of mental illness creates a public image of impacted people that includes "blemishes of individual character," (Pescosolido 2013).

### ***Stigma Mechanisms***

Since current research on mental illness stigma is so broad, and encompasses many different forms and iterations, this study will utilize a framework from Annie B. Fox and colleagues in their study for the Department of Health & Human Services journal, *Stigma Health* (Fox, Earnshaw, Taverna, Vogt et al 2018).. This study uses a Mental Illness Stigma Framework (MISF) to explore three mechanisms that encompass the ways in which people that do not have experience with mental illness stigmatize those that do. These mechanisms include stereotypes, prejudice, and discrimination; all of which include a variety of harmful ways that these mechanisms are carried out (Fox et al 2013).

Stereotypes of people with mental illness are primarily driven by their “dangerousness, rarity, and responsibility,” as perceived by the stigmatizer. Fear, pity, and anger are the most common prejudices, and discrimination is most commonly experienced as ‘withholding of help, avoidance, segregation, and coercion,’ (Fox et al 2018). The stigmatized population experiences mental illness stigma in a variety of ways that are explored in this study: experienced stigma, anticipated stigma, and internalized stigma (Fox et al 2018). One rather insidious stereotype that is often expressed about people with mental illness is a perceived threat of violence (LeBlanc and Kinsella 2016). This negative stereotype was a huge driver in forced institutionalization, and still contributes today to coercive or mandated treatments (LeBlanc et al 2016).

These negative stereotypes are harmful in that they subjugate these bodies in very material ways, but they also create shame and negative emotions internally among people with mental illness (Thornycroft 2020). In the article *Crip Theory and Mad Studies*, Thornycroft includes a powerful quote from a person narrating their experience with this form of internalized oppression: “Once oppression has been internalised, little force is needed to keep us submissive.

We harbour (sic) inside ourselves the pain and the memories, the fears and the confusions, the negative self images, and the low expectation, turning them into weapons with which to re-injure ourselves, everyday of our lives,” (Thorneycroft 2020).

Negative self-perception among this population occurs because of these overarching stereotypes, and it is not difficult to understand why people with mental illness may feel they are ‘incompetent’ or ‘incapable’ in their provision of treatment, or in their provision of material resources for survival (Thorneycroft 2020). Social workers dedicated to the empowerment and dignity of the individuals they are working with must be aware of the internal effects of this type of stigma, work to deconstruct these perceived notions, and understand the defeat their clients may be feeling based on these negative self-perceptions.

Fox and colleagues note that a limitation to mental illness stigma and effective interventions is the broadness of mental conditions and their manifestations, creating a barrier to inclusive language or advancements in research (Fox, Earnshaw, Taverna, Vogt et al 2013). However, they also believe that a more broad approach to measuring this type of stigma can span across many diagnoses and experiences, making way for more macro-level changes in discrimination (Fox et al 2013). They also state that adopting a larger umbrella of mental illness framework that focuses on the larger concepts of ‘stereotypes, prejudice, and discrimination,’ is useful because the stigma experienced across a broad spectrum of mental illnesses is felt very similarly when it’s broken down into these categories (Fox et al 2013).

### ***Structural Consequences of Mental Illness Stigma***

In their study *Structural Levels of Mental Illness Stigma and Discrimination*, Patrick W. Corrigan, Fred E. Markowitz, and Amy C. Watson, explore the ways in which government and other social institutions discriminate against people with mental illness both intentionally,

through rules or policies, and unintentionally, through exclusionary school admissions processes (Corrigan, Markowitz, and Watson, 2004). This study discovers how discrimination is played out through governmental policies and laws. At the time that their article was published, over one-third of 50 states in the US still restricted people with mental illness from voting, holding office, being a part of a jury, and in some cases, being married or having custody of their children (Corrigan et al 2004). These types of policies are built on the assumption that people with mental illness are incompetent due to a vague idea of what the label actually means (Corrigan et al 2004). Authors note that these types of policies tend to stay active unless there is active motion to change them, which does not occur often, so this legal discrimination likely persists in some states (Corrigan et al 2004).

Another form of discrimination the authors note is the negative portrayal of people with mental illness in the news media (Corrigan, Markowitz, Watson, 2004). A major focus of the news media in their portrayal of this group is their perceived ‘dangerousness.’ It is said by the authors that studies have shown that 86% of published stories about people with mental illness tend to highlight violence, perpetuating this notion of dangerousness, while other stories heavily lean on other negative stereotypes, like assumed ‘unpredictability’ or ‘unsociability’ (Corrigan et al 2004).

Some forms of structural discrimination toward people with mental illness are less direct, but nonetheless result in fewer opportunities for those affected. According to Corrigan, less funding is given to research for and treatment of mental illness than is given to, say, cancer research and treatment, as health disorders like cancer and heart disease dominate the healthcare field in the USA, so those with mental illness or substance use disorders are not given the adequate treatment to aid them in recovery (Corrigan et al 2004). Additionally, some insurance

claims do not allow for the treatment of mental illness, even when attempts to cover them are made. For instance, while the Mental Health Parity Act (MHPA) of 1997 was meant to aid in the treatment of people with mental illness, employers were not required to provide this type of coverage, people with substance use disorder were not covered, and a company was exempt if they did not have more than 50 employees (Corrigan et al 2004). This major gap in treatment leaves these people vulnerable to the effects of their condition, as well as further discrimination and barriers to resources and opportunities.

### ***Interventions on Mental Illness Stigma***

Despite extensive research on the existence of mental illness stigma, very little has been published about the efficacy of interventions to prevent this stigma. In this thesis, I follow Brewis and Wutich's suggestion that proximity to the first person narratives of people who experience mental illness could foster greater understanding and reduce stigma. (Brewis and Wutich 2022). Efforts to reduce mental illness stigma might include training in workplace settings to raise awareness, studies to track the quality of stigma experiences, public announcements that state the potential harms (Brewis and Wutich 2022), and public protest.

However, none of these efforts have significantly reduced stigma of mental illness among the public (Corrigan et al 2010), or among service providers (Brewis et al 2022). Another common intervention thought to remove mental illness stigma is direct contact between stigmatizer and the stigmatized (Corrigan et al 2010). Unfortunately, so many of these interventions fall short, both because of the deeply embedded social norms that exist to classify people as “normal” or not, and because these interventions sometimes run the danger of reinforcing stigma instead of reducing it. Some interventions have been shown to foster empathy towards the stigmatized population, but when it comes to the willingness of the stigmatizer to be

within proximity to the individual or group with mental illness, little has changed (Brewis et al 2022).

Thorneycroft borrows from Butler and Spivak the idea of *strategic essentialism* as a feature of Mad studies that functions to change dominant ideas of mental illness by using lived-experience narratives in academia and activism (Thorneycroft 2020). Thorneycroft mentions that experiences of mental illness are often ‘homogenis[ed],’ as traditional essentialism would have it, and the tool of strategic essentialism better speaks to the spectrum of experiences and ways of being that better encompass the scope of the lives of people with mental illness. Strategic essentialism is used as a tool, like essentialism, to “normalize” the dynamic experiences of mental illness, rather than pathologize these experiences and further the stereotypes about them. The utilization of these narratives in our education and practice is a means to ‘better rights and service,’ as they can be better fit based on the direction of the individual (Thorneycroft 2020).

### **Mad Studies and Disability Justice**

This section introduces the Mad studies framework and explores the historical movements that paved the way for its development. It delves into the social implications of the term ‘mad,’ and why its use in this context is intentional and political. This history of psychiatry in the United States is explored in order to better explain the origins of Mad movements, and the subsequent collaboration with various social and political movements that led to the introduction of Mad studies among psychiatric survivors. Following this section, contemporary disability discourse is explored, and importantly, the distinction between sanism and ableism is made, in order to separate oppression based on mental illness and physical, or often more visible, forms of disability.

### *History of Mad Movements*

The term *Mad studies* was first introduced at a conference at Syracuse University in 2008 by Robert A. Ingram, a psychiatric survivor formerly enrolled in Disability Studies at Ryerson University in Toronto, Ontario (Ingram 2016). While at Ryerson, Ingram was given the opportunity to journal extensively about his experience with mental illness and explore limitations he found within Ryerson University's school of Disability Studies. Through his research, he learned that people experiencing "madness" while enrolled were still prevented from fully participating in academia based on their disability status (Ingram 2016).

The term 'mad' as a way to describe people in mental duress has historically held negative connotations and has been used in ways that are meant to degrade or denounce the subject. According to Menzies and LeFrancois, participants in Mad movements over the last century have used the word 'mad' politically, in order to reclaim the term and replace the adherent oppression with "dignity and pride," not unlike the contemporary reclamation of words like 'queer' and 'fat,' words that simply describe distinctly human experiences (Menzies, LeFrancois, Reaume, 2019). This rejection of the negative connotations associated with such words is a means to normalize the experience and means of identification within these systematically marginalized groups (Menzies et al 2019). Although this reclamation of language can be empowering for some, it is important to note that not everyone included in these marginalized groups, or even within these types of radical social movements, is comfortable using these terms because of the trauma attached to the harassment and violence many have experienced as a result of such identities.

Although Ingram coined the term Mad Studies, he does not take credit for creating the model. He notes that there have been various "mad movements" throughout history, like those of



the 1960s and 70s in Canada, movements that protested the inhumane nature of involuntary psychiatric confinement, from which this model takes inspiration from (LeBlanc et al 2016). After World War I and the vast closure of mental asylums in North America, the psychiatry field was booming in the wake of various new technologies and the development of the first iteration of the Diagnostic and Statistical Manual, or the DSM. The 1970s brought a surge of new psychiatric medications like Lithium and Prozac to the masses, which led to diagnosis of various mental conditions en masse (Menzies et al 2019). These massive advancements in the psychiatric and mental health fields created backlash among organizations and groups of activists within and outside of the affected communities. These people in opposition to the new, dominant “psychiatry society” were especially critical of diagnoses based along the gender binary, and those based on racist and homophobic pathologization, involuntary confinement and treatment, and cruel physical ‘treatments,’ like electroshock (Menzies et al 2019). A common theme among these treatments and others is that they were being forcibly thrust upon people based on artificial standards of normalcy and what was considered to be socially acceptable behavior.

While this rapid construction of dominant psychiatry was happening in the Americas, anti-psychiatry movements in Europe brought attention to the “dehumanization” of people experiencing mental illness through these new developments in psychiatric science (Menzies et al 2019). The idea that mental illness should be understood by those that experience it was gaining popularity among these thinkers (Menzies et al 2019). Collaboration between those harmed by psychiatry and their allies gained traction. This was referred to as the ‘mental patients’ liberation’ and the ‘c/s/x (consumer/survivor/ex-patient) movement in Canada and the United States, and in Europe, the ‘psychiatric survivor’ and ‘service user’ movements (Menzies et al 2019).

As this movement was gaining popularity among the counterculture, other progressive social movements of the time, like second-wave feminism and the child rights movement, were linking the intersections of this cause to mad movements. The dominant forces of the institution of psychiatry continued to fight back. They argued, for example, that deinstitutionalization led to the widespread social deterioration of those that had been institutionalized, as they were often left houseless and without many supports once released from the asylum system, neglecting to address the lack of social supports coming from the governments under which these people reside (Menzies et al 2019).

Despite resistance from the psychiatry community, survivors and activist movements continued to grow and spread to regions outside of the Americas, and a plethora of organizations emerged from their efforts. More commonly known organizations among the mental health community included MindFreedom International (MFI) and the Hearing Voices Network (HFN) (Menzies et al 2019).

Eleanor Longden, a psychologist and the founder of HFN, had schizophrenia and experienced hearing voices in her head that increasingly affected her life in a negative way. Her experience in the mental health system included many instances of hospitalization and medications based on her presumed ‘insanity,’ but it wasn’t until she started listening to her own voices, instead of fearing them, that she could begin to recover from the agony she was facing (Ronson 2022). Longden performed a TEDTalk about her experiences called *The Voices in My Head*, which boasts over 2.3 million views on YouTube. She says of her experience in the Ronson article:

“The voices took the place of overwhelming pain and gave words to it – memories of sexual trauma and abuse, rage, shame, loss,

guilt and low self-worth. Probably the most important insight was when I realised that the most menacing, aggressive voices actually represented the parts of me that had been hurt the most – and as such, it was these voices that needed to be shown the greatest compassion and care. Which of course ultimately represented learning to show compassion, love, and acceptance towards myself,” (Ronson 2022).

Longden’s words are a testament to the peace that can come from acceptance from the self, and acceptance from those around her, instead of the common experience that she faced from the medical system to change or fix what she was experiencing.

### ***Disability Justice***

While the dual effects of ableism and sanism are important to examine, it can be said that societal subjugation of people with both disabled bodies and disabled minds are similar, in that the medical field, and even broader society, are under the impression that disabilities need to be subject to ‘alter, control, or repair’ (Thornycroft 2020). Often, the goal in treatment of disabling conditions involves practice meant to correct the person in attempts to make them appear more ‘normal,’ and their ‘abnormalities’ have left them vulnerable to various types of violence, including, but not limited to; confinement, involuntary lock-up in asylums and prisons, and ‘physical, sexual, and emotional violence,’ (Thornycroft 2020). Sanism intersects with various other matrices of oppression, creating a compounding effect that contributes to further risk of discrimination, violence, and even death (Thornycroft 2020).

The development of the internet made connection between international groups much simpler, and made the creation of such organizations as MindFreedom International possible

(Menzies et al 2019). The internet has also been a place for service users to chronicle the coercive services and violations of rights they have experienced in the medical and psychiatric fields. This type of connection based on shared-experience, or consciousness-raising, has been incredibly important for survivors, as they were able to be validated in their experiences of medicalization, and made possible the sharing of ideas, and further questioning of the medical model of mental health (Newman 2019). Internet activism in this realm has taken many forms, from the Facebook group Drop the Disorder, holding over 8,700 members, to websites by critical psychiatrists themselves, allowing survivors plenty of opportunities for building community (Newman 2019).

Ingram introduced Mad studies as an emerging field of *in/discipline* at the Durham Conference in 2008. His wish was that this model would disrupt academia by creating a place for the voices of those with mental illness. He challenges the idea that psychiatry is objective, and proposes that the real experts on mental illness are those that have lived experience with mental illness (Ingram 2016).

### **Sanism and Intersectionality**

This section begins by explaining intersectionality theory and in what ways it is often used in education regarding power and oppression. Contemporary discourse about intersectionality addresses oppressive matrices, such as race, gender, class, sexuality, and ability, and the ways in which they interact. However, sanism is a term not commonly used in literature about intersectionality, so the following sections highlight the unique ways in which oppression and discrimination occur for people with mental illness, and why this form of oppression should be more visible and should be seen as distinct from ableism based on physical disability.

### ***Intersectionality Theory***

Intersectionality theory was introduced by Kimberle Crenshaw, a lawyer, civil rights leader, and Black feminist theorist, in 1989, to bring attention to ‘vexed dynamics of difference and the solidarities of sameness in the context of antidiscrimination and social movement politics,’ (Cho, Crenshaw, and McCall 2013). Intersectionality theory provides an important framework for looking at axes of power and oppression, and the overlapping oppression that occurs when holding identities in multiple marginalized groups. Social categories analyzed through this lens have traditionally been race, gender, class, sexuality, nationality, and ability. Critics of this theory have posited that this categorization tends to promote understanding identity in binary terms while ignoring the complexities in the lives of people in these marginalized groups (Cho et al 2013). These critiques are important because they open up conversations about what it means to exist in groups oppressed by social, political, and cultural dynamics, and the dynamics within and between social categories or identity groups (Cho et al 2013). In this study, I explore one of the complexities within contemporary conversations about oppression based on a person’s dis/ability, by separating the oppression based on one’s mental condition from homogenous ideas of disability.

### ***Sanist Oppression***

Sanism, sometimes referred to as mentalism (Wolframe 2012), is an idea stemming from intersectionality theory, which states that individuals’ and groups’ holding marginalized identities experience unique forms of oppression and discrimination based on their overlapping marginalized identities (Corrigan et al 2018). For example, a cisgender man experiencing racism will have a different experience with racism than a cisgender woman who is experiencing them. Sanism can be defined as an oppressive system that affects people with mental illness and

contributes to stereotypes and prejudices that directly leads to discrimination of them in avenues, such as employment, education, health care, and living independently (Thorneycroft 2020).

Often, sanist oppression is veiled in ableism and disability discourse, but it is crucial to separate both types of discrimination in order to understand their unique machinations in the lives of people with varying disabling conditions. Thorneycroft highlights this distinction by defining ableism as the idea that ‘the abled body is natural and normal,’ while borrowing a definition from Van Veen to describe sanism as ‘ways in which society values certain forms of consciousness and being over others’ (Thorneycroft 2020). Thorneycroft’s idea is that society’s ‘preference, expectation, and command for the sane mind’ is where the ‘loathing of mad bodies’ is born and continues to systematically subjugate them (Thorneycroft 2020).

Double-Disadvantage theory speaks to this overlapping of oppressions, and suggests that this overlap pushes people further into the margins (Corrigan et al 2018).

### **Social Work Perspectives**

Since the profession of social work prioritizes the dignity and worth of participants, and reducing stereotypes (NASW), research within the discipline has highlighted the importance of Mad Studies. This section provides tangible accounts of this framework being used by social workers in practice and highlights the important insights that those social workers gained by applying this knowledge to practice.

Evidence of the efficacy of Mad studies frameworks for social workers has been recorded. Two recent MSW graduates in Canada, Kathleen MacPhee and Lynsey Wilson Norrad, chronicled their experiences of exposure to Mad studies in their postgraduate program (MacPhee et al 2022). They journaled about the “unlearning” they went through as a result of this knowledge, and how they instead learned to collaboratively center the experiences of their clients

with them in their work. They write about *critical reflexivity* as a crucial tool in their unlearning process, which required them to interrogate their own assumptions of mental illness, as well as disrupt the complicity they had in perpetuating the oppression of this population (MacPhee, et al. 2022).

Wilson and MacPhee wrote in their journal entries about disrupting the faulty cultural ideas of what is considered normal and healthy (MacPhee and Wilson 2022). They write about their new understanding of sanism as a largely invisible systematic oppression and the ways in which it paints people with mental illness as “incompetent,” among other stereotypes. These prejudices can link to other forms of oppression individuals may be facing, such as racism. The two social workers explain how this lack of understanding of the complexities of lived experience further pathologizes clients with mental illness, and works to further the dominant idea that to work with someone with mental illness is to try to change them, instead of to work collaboratively with their needs and desires (MacPhee et al 2022).

### **Production of Knowledge**

This section begins by describing the ways in which knowledge production occurs in academia and other institutions, and that power players in the dominant production of knowledge systematically exclude the voices of people with mental illness in knowledge of their own experiences. The injustice that this system creates is discussed, and a suggested solution is explored. The following section considers the crucial places in which this exclusion exists and where it can be included in order to diversify knowledge of experiences of mental illness among service providers and academics.

### ***Epistemic Injustice***

Dominant hegemonic processes of knowledge production systematically leave out perspectives of those experiencing mental illness, as this population is commonly discredited as being reliable sources of knowledge. “Legitimate knowers” (LeBlanc and Kinsella 2016) are often those with academic or institutional accolades that dominant structures deem worthy of knowing, and marginalized populations are often left out of this system, and their lived experiences are not included in what it means to live with mental illness. Dominant ways of knowing pathologize bodies and further the idea that people with disabled bodies or minds should be subject to change due to the ‘unnatural’ nature of their conditions (Thorneycroft 2020). In dominant discourse among those working with people with mental illness and psychological conditions, psychocentrism is the ruling ideology, privileging minds that are not seen as ‘problematic’ (Thorneycroft 2020).

LeBlanc and Kinsella refer to this exclusion of people with mental illness from knowledge production as *epistemic injustice* (LeBlanc et al 2016). People with mental illness, in this case, are marginalized based on their diagnosis, and the lack of their experiences in dominant knowledge structures furthers prejudices and pathologizes them and keeps them from having autonomy over their care and treatment (LeBlanc et al 2016).

Related to epistemic injustice is the idea of *epistemic reflexivity*, the practice of bringing a critical lens to disciplinary knowledge and understanding how that knowledge was produced and who was left out of that process (Kinsella and Whiteford 2008). A Mad studies lens in social work could inspire this form of reflexivity by recognizing the exclusion of Mad perspectives in academic knowledge. Epistemic reflexivity could pave the way for epistemic justice for Mad persons by reminding social workers to primarily use the knowledge of the people they are



serving in their direction of care and treatment, instead of only adhering to dominant knowledge structures common in medical and psychiatric spaces.

### ***Exclusion of Mental Illness Perspectives***

The exclusion of lived-experience narratives of mental illness from dominant epistemologies is systematic, and is a result of prejudice and discrimination of this group, which works to discredit their knowledges. LeBlanc and Kinsella quote activist Erick Fabris in their article; "...we are not even credited with having experience; we are thought to have lost our minds, to be unreasonably emotional, possibly at the worst of times, a kind of philosophical exemplar of inaccessible life," (LeBlanc and Kinsella 2016).

The authors propose that a direct result of sanism is a "negative identity prejudice," which perpetuates stereotypes like those that Fabris mentions, among others, and a sort of educational gatekeeping occurs. This type of exclusion is insidious, because since it perpetuates these negative stereotypes, this type of discreditation becomes justified, creating something the authors call "testimonial injustice." The exclusion of these narratives creates an incomplete picture of what it means to experience mental illness and will continue to allow social workers and other professionals to provide treatment and care based on the epistemologies they were exposed to, rather than the needs and desires of the people they are working with.

### **Methods**

This section will include the methodology I used in order to uncover where Mad studies and sanism exist in the MSW curriculum during the 2022-2023 school year. I explain how I conducted this analysis of the curriculum, as well as how I conducted research for the literature review. Also included in this section is the set of questions I asked each professor that I interviewed.

## **Overview of Methodology**

For this study, I conducted a qualitative case study (Merriam and Tisdell 2009), consisting of a descriptive analysis of required foundational year syllabi in the Masters of Social Work program at Portland State University during the 2022-2023 school year. A survey conducted with the lead instructors in the MSW program will provide information about how curriculum is chosen for each course and if Mad studies framework and lessons on sanism are present in either required or optional reading for each course. Lead instructors were chosen for interviews as they are responsible for developing the course syllabus template that all instructors teaching that course can adopt and/or choose to modify for their instruction. A review of literature will include background information about foundational stigma research, existing mental illness stigma frameworks and research, mental illness stigma interventions, why certain approaches have worked or have failed, Mad studies framework, and sanism in conversations of intersectionality and oppression.

### ***Literature collection***

Literature was collected on mental illness stigma frameworks, social distance scales, sanism as an oppressive structure, foundational information on Mad studies model, and efficacy of stigma frameworks. Literature was found primarily by using the PSU Library database on the Library homepage by typing key words and phrases into the search bar. Keywords and terms used included “mental illness stigma,” “structural stigma,” “mental illness stigma and trauma,” “Mad studies,” “Mad studies in social work education,” “sanism,” “sanism in intersectionality.” Reference pages for chosen articles were reviewed for further suggestions for research. I reached out to PSU SSW faculty Stephanie Wahab for literature suggestions, who introduced me to Mad studies frameworks, and the book *Lazy, Crazy, and Disgusting*. Further suggestions for literature

were provided by my thesis advisor, Samuel Gioia, and PSU MSW faculty member, Michele Martinez-Thompson. Journal articles were saved to Zotero software and eliminated for lack of relevant information to the study, and key articles were saved and used for the study.

### ***Syllabus Review***

I analyzed materials found in the curriculum of the foundational year syllabi in the MSW program for the 2022-2023 school year. I conducted a qualitative content analysis (Merriam and Tisdell 2009) of all lesson plans, required readings and materials for mentions of Mad studies frameworks, and for “sanism” in discourse around oppressive structures. I chose to analyze foundational year syllabi, because they consist of the courses that all students in the MSW program are required to complete for graduation. Courses being covered in the Foundational year are SW515 Skills for the Helping Process (Groups), SW520 Social Welfare History and Policy, SW530 Social Work Practice with Individuals and Families I, SW 531 Social Work Practice with Individuals and Families II, SW 532 Advocacy and Empowerment, and SW 539 Social Justice in Social Work.

Optional readings provided by syllabi are not analyzed as those materials are not presumed to be read by every student in the program. Through all the syllabi analyzed, several listed resources were eliminated from analysis because of broken links to journal articles, videos that were inaccessible due to subscription restraints, or inaccessible chapters of books. Required textbooks were not analyzed as the bulk of material within them was beyond the framework of this study. This gap in research will be addressed by interviewing the course leads in the MSW program about how they choose which material will be used in each course curriculum.

### ***Survey of Current MSU Lead Instructors***

I conducted interviews with several lead instructors for courses in the MSW program at Portland State in the 2022-2023 school year. Zoom meetings were set up with instructors, and conversations with each lead lasted about an hour. Questions asked included the following:

- In your course, where is the importance of lived experience of MI being introduced?
- What is your awareness of a Mad studies framework?
- What is your awareness of *sanism* in conversations of intersectionality?
- How do you and other course leads decide what material is included in the curriculum?
- How do you come to a consensus about what is important to keep, and what needs to be changed?

Research memos were conducted to keep record of their answers, and to record my thoughts and analyses of the conversations.

### **Findings**

My content analysis of the MSW foundational curriculum syllabi brought about no instances of either ‘sanism’ or ‘Mad studies.’ I asked lead course instructors about their knowledge of these concepts and was given mixed answers. One instructor and one faculty member were unaware of Mad studies when asked about it by name, but were aware of the importance of lived-experience accounts of mental illness, and one instructor shared a syllabus with me from an elective in the Advanced Clinical Track where lived-experience accounts were utilized throughout. In this course, SW 555: Social Work Perspectives on Mental Health Disorders (Adults), lead instructor Professor Eddie May and other faculty teaching this course introduce students to mental disorders as they are defined by the DSM-5, while analyzing the biological, social, and cultural variables that contribute to these definitions and perceptions of

mental disorders. They employ a social work lens to work with these populations in a way that upholds values of social justice. The introduction of each mental disorder is supplemented with a real-life account of someone who lives with this mental condition. Professor May echoes many professors in the SSW in his belief that using the DSM-5 as a diagnostic tool without employing a critical lens can contribute to the essentialism of mental disorders if lived-experienced accounts are not examined.

Other faculty members were aware of Mad studies and anti-psychiatry movements in the field, but explained to me that the process in changing curriculum is complicated, and involves many people and hierarchical decisions ultimately made through the Council on Social Work Education's Commission on Accreditation (COA) (CSWE 2023). The faculty I spoke to were receptive to the purpose of my research and assured me that although that process can be complicated, this type of research is important in a field in which language and practice is ever-changing. One professor spoke about the places in which they were aware of lived-experience accounts in the curriculum, but stressed the importance for language around frameworks, like 'Mad studies,' as a tangible concept for students to grasp and use in their practice. This professor suggested that I provide literature that I found to be foundational in my knowledge of this framework and its implications, so future curriculum can hopefully be informed by my research.

### **Implications for Social Work Education**

This section begins by making suggestions for ways in which social workers can use Mad studies perspectives in their practice. Suggestions are made for practice in the mental health field, as well as for social work educators. I provide multiple suggestions for literature that social

work educators can use in their curriculum to introduce students to this framework. I conclude this section with suggestions for future research.

### ***Implications for Practice***

Social workers in the field of mental health, or in other fields in which they encounter people with mental illness, can use this research to inform their practice in crucial ways. Using the knowledge Mad studies provides, reminds social workers that their direction of services for those with mental illness should be directed by them. The first step in delivering client-directed care is the careful consideration of their needs and desires, as indicated by the client themselves, not according to what the social worker believes that person needs. As stated previously, traditional practice is directed by the practitioner's beliefs about what a person needs, and those beliefs are a direct result of the essentialism of mental illness that historically works to 'contain, regulate, classify, govern, monitor, and violate crip and mad people,' (Thorneycroft 2020). Mad studies in practice deconstructs the idea that people with mental illness are to be fixed, or that people living with mental illness want to be cured of their condition.

Critical reflexivity, as introduced earlier, can look in practice like the cycle of self-reflection; a constant checking and re-checking of one's interactions with their clients with mental illness (MacPhee and Wilson 2022). I see it as an evaluation of self that works specifically to ensure that the practitioner is aware of the power dynamic between themselves and the individuals they are working with, and an ever-present reminder that although they are the social worker assigned to assist with these individuals' or groups' issues or social barriers, it is up to the individual to decide which aspects of their lives or conditions they want help with whenever possible. Mad studies uses critical reflexivity also to remind the social worker of the social constructs of the individual's condition, including the social, political, and historical

contexts of their lives, instead of focusing on the perceived deficits of their mental illness. These social conditions are ever-changing, and critical reflexivity would remind the social worker to always evaluate the positions in which their clients are sitting in relation to these contexts.

Social work educators can introduce Mad studies as a supplemental, alternative way of learning about mental illness, which is traditionally done so using the guidance of the DSM-5. I am not suggesting here that the DSM-5 not be used in the mental health field at all, only that it is looked at with a critical lens; one that looks at it not as a finite tool, but as one of many in which mental health professionals can use to serve their patients. I hope that an introduction to a Mad studies framework among social work students will make for a generation of mental health professionals that are critical of essentialist ideas of mental illness. I hope Mad studies can open social workers up to leaning into the idea that their clients are the experts in their experiences, and that they are simply there to help navigate them through the system whichever way the client sees fit.

### ***Suggested Resources for Social Work Educators***

In the course of my research, I discovered many texts that could further inform social workers and other service providers working with people with mental illness. Specifically, my suggestions are for professors in the School of Social Work, both in bachelor's and master's programs, to include this information in their courses. While I understand that the construction of a course shell requires many intricate considerations, I hope that my research conveys the importance of highlighting epistemic injustice, and the consideration of lived-experience narratives of mental illness.

My first suggestion for literature is the article *Toward Epistemic Justice: A Critically Reflexive Examination of 'Sanism' and Implications for Knowledge Generation* written by

Stephanie LeBlanc and Elizabeth Anne Kinsella, both of Washington University, written for the journal *Studies in Social Justice*. This article was my introduction to the idea of *epistemic injustice*, and the ways in which this type of injustice subjugates those individuals with mental illness by excluding them from the dominant production of knowledge. Professors could use this article in their curriculum to remind social work students that the traditional education system that we operate under systematically discredits the voices of people with mental illness, which is a product of the sanism they are subject to in the greater society. Social work students that read this article will be introduced to Mad studies, sanism, and to more effective means of practice that alert them to taking into consideration the knowledges of those they are working with.

My next suggestion is the article *Professional education and Mad Studies: learning and teaching about service users' understandings of mental and emotional distress* by John Newman, Kathy Boxall, Rebecca Jury, and Julie Dickinson for the journal *Disability & Society*. This article successfully explains the mission of Mad studies in professional education, while including narratives of people with lived-experience, and including them in the authoring process.

The Newman et al. study is unique to other literature I found, as it actually used the narrative experiences of one of the authors in order to demonstrate how this could be done in practice. Social work students were asked to share their ideas of mental illness, then be exposed to the authors' lived-experience accounts of their mental illnesses. Students were then told to re-analyze their perceptions of mental illness, specifically what it means to hear voices. Many of them realized that their original perceptions of this form of mental illness were perhaps incorrect, and that their exposure to the authors' experiences opened their eyes to more ways of understanding. Social work professors can use this article to show students how they can put



lived-experience accounts into practice and how to garner better understanding of their clients' lives.

The last suggestion I will list here is for the article *Introducing Mad Studies* by Robert Menzies, Brenda A. LaFrancios, and Geoffrey Reaume, for the book *Mad Matters*. This article was crucial for my exploration of Mad studies, and where its origins lie. It was impossible to get a full understanding of this model without examining the historical, cultural, and political roots of the mad movements of centuries past, and this article provided much of that knowledge. The history of the psychiatric movement and the proliferation of Big Pharma provides readers with context of capitalism's role in the subjugation of disabled bodies and minds, and privileging of those that are 'normal' and socially compliant, and the pervasive control and violence inflicted on these people to this day (Menzies et al 2019).

The article also examines the intersectional effects of sanism with various matrices of oppression, and the compounding effects of belonging to various social categories. I suggest this literature because, in my experience in the School of Social Work, I have been exposed to intersectionality discourse plenty of times, and have examined it in many ways. However, sanism was a piece of intersectionality that I had never been exposed to, and I find it to be incredibly important to consider. This article does highlight those experiences and, in my opinion, social work students must be exposed to it in order to best understand the complexities of their clients' lives. This article can do just that. As students dedicated to social justice, our knowledge of dynamics of power and oppression should be as well-rounded as possible, and intricacies of concepts like ableism should be cracked open to reveal the spectrum of experiences within them.

Samuel Gioia, BSW Professor at Portland State and my advisor for this thesis, shed some light on the ways in which curriculum is built within the program, and the difficulties that may

arise in the process of change. Though accreditation of social work programs occurs through the Council on Social Work Education (CSWE), programs are built within particular schools by selected faculty. Curricula are built within the MSW program and the BSW program, and then are to be reviewed roughly every five years, but are otherwise fairly set in stone between reviews. Unfortunately, this means that creating changes within the program curriculum can be challenging if the change is not glaringly urgent.

Lead instructors in the MSW program review and approve syllabi for their respective courses, and other professors teaching those courses use those syllabi as a guide that they can adopt or adapt based on their preferences. I propose here that the review of syllabi, whether by lead instructors or by the overarching review committee, includes lived-experience accounts of mental illness, and provides a framework for using these lived-experience narratives in practice. I believe that an introduction to Mad studies and sanism can provide social work students with tangible evidence in favor of using their clients' narratives in their direction of practice with people with mental illness.

### ***Suggestions for Future Research***

One issue with lived-experience accounts of mental illness that I found in my research is the threat of reinstating essentialist ideas of mental illness through these narratives (Thorneycroft 2020). Our brains are designed to make judgments and categorizations quickly, and narratives of lived-experiences of mental illness without critical examination can reinforce stigma or objective ideas of certain conditions, even among the most seasoned professionals (Brewis and Wutich 2019). Our culturally prescribed ideas of what is 'normal' or 'right' can influence mental health professionals, even when equipped with the knowledge of lived-experience, and they will provide care and treatment based on those norms, not on the needs or desires of their clients

(Brewis et al 2019). Activists in the movement for rights of mad people, even Eleanor Longden and her accounts of her own experience, have been criticized for their potential in pathologizing what it means to have a mental illness. Although I am advocating for the inclusion of these voices in the educational process for social workers, I would like to know more about why this sometimes can have the opposite effect than is intended in these movements.

A related risk is the threat of tokenism, or what some people are referring to as “inspiration porn.” Stella Young, a journalist who uses a wheelchair, spoke at a TEDTalk about her experience with people who have viewed disabled people as “objects of inspiration,” whose everyday dealings are seen as accomplishments (Young 2014). Young says that because our society views disability as a “bad thing,” by being disabled, you are exceptional (Young 2014). I think it’s interesting that some people with disabilities are vilified, while others are made out to be tokens to look up to. These ideas are based on social constructs that dictate who is worthy of fair treatment, and I’d be curious to know more about what those differences are, and how people decide, whether implicitly or explicitly, who is worthy.

### **Conclusion**

The stigma of mental illness is a complex problem that creates individual, social, structural, and systemic problems for those with lived-experience. It has been suggested by stigma researchers that one possible solution to this form of discrimination is stigmatizers’ being in proximity with people with mental illness, which includes taking into account their lived-experience narratives in order to gain a better understanding of their needs and desires. Professionals working in the field of mental health can also perpetuate this type of stigma, and provide care and treatment based on what they believe the patient needs, not what the patient is telling them they need. This type of practitioner-directed care can often be coercive or

ineffective. It also runs the risk of re-traumatizing the client, leaving them more vulnerable to the effects of their mental illness, and does little to deconstruct structural barriers for the individual, like employment or access to healthcare or housing.

Because this risk is very real for people with mental illness, I propose inclusion of a framework for using their lived-experience accounts in the production of knowledge for social work students. The inclusion of Mad studies and sanism in the social work curriculum not only highlights the voices and desires of those with mental illness, but it provides tangible ways for students to use these voices in their direction of practice when they are out in the field. I believe this knowledge, often left out of dominant epistemologies, can foster better understanding, empathy, and dignity of the individuals the social worker is providing care for. Most importantly, I think this piece of education and practice among service providers can shrink the stigma and negative stereotypes that pervade people with mental illness in the field of social work. My hope is that this knowledge can remind social workers that the experts in their clients' lives are their clients, and that their voices are the ones that matter when it comes to their care and treatment.

This study has given me tools that will help me be a more compassionate person in the field and outside of it. I understand more about what it means to be self-reflexive in my education process and in my work to ensure that individuals I am working with feel safe and in control. I have learned that being critical of dominant pedagogies in a field like social work is crucial, and that plenty of new ideas are to be discovered in new perspectives. Throughout the research process for this thesis, I found many avenues through which I could continue to study that were outside of the scope of this thesis, but that I plan to investigate post-graduation. This project has made me excited to continue to learn and uncover new ways of thinking, and I hope to be able to explore those avenues in the masters program.

***Key Terms***

*Mental illness, Mental illness stigma (MIS), Mad studies, sanism, lived-experience, essentialism*

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