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Health Literacy and People Diagnosed with Mental Illness

by

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A dissertation submitted in partial fulfillment of the
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in
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Abstract

Health literacy is a well-studied concept that has a large literature base. Yet, little is known about health literacy and people diagnosed with mental illnesses, and even less health literacy research speaks to people diagnosed with mental illness. I used a framework and approach of lived experience of psychiatric diagnosis and psychiatric survivor research to conceptualize and inform the study. It explores health literacy with people diagnosed with mental and physical health diagnoses using a small quantitative survey, focus groups, and an individual interview. The findings suggest that health literacy is a dynamic and complex construct that interacts with the individual across the layers of an ecological model and over time. Relational, trust-based practice with a primary care provider is viewed as supporting health literacy. In addition, trauma-informed and culturally responsive care also can strengthen health literacy. In contrast, participants describe the emergency department as a place within the healthcare system where they commonly encounter barriers to health literacy. Other barriers to health literacy include coercion, lack of trust, lack of credibility, lack of informed consent, and iatrogenic experiences with the healthcare system. More research is needed to understand the complexity of health literacy and how it interacts with diverse people and structural elements of the healthcare system.

Dedication

> “There's really no such thing as 'voiceless'. There are only the deliberately silenced or the preferably unheard.” *Arundhati Roy*

This dissertation is dedicated to all the people who have been diagnosed with mental illness and have been dismissed and spurned by healthcare providers that have caused them delayed healthcare and even their lives. It is also dedicated to healthcare providers who take time to listen to people deemed “less than” for whatever reason. To Madgrrls all over the world. I couldn’t have done this without you!

Acknowledgments

I stand on the shoulders of many people who came before me and buoyed me up along this long and lengthy journey. I want to thank all my cheerleaders who have supported me throughout this process. Thank you to Carla Green who started me on this journey by sending me an email with the link to apply to the PSU MSW program with only one word in the email: “Apply!”. To the therapists that believed in me even when I could not believe in myself: Bill Ribicki, Francis Harris, Genny Bimslager, and Cinda McKitrick. I am grateful for the support you provided me over the years.

Susan Stefan and Priscilla Ridgway, you have been both friends and mentors to me and made me feel so not alone in the world. Thank you, my dear friends. I love our conversations. I’m looking forward to conversations where I do not have a deadline to meet!

Bowen McBeath, Laurie Powers, Junghee Lee, and Christina Nicolaidis: Thank you for your mentorship and friendship throughout the years. You have helped me become who I am today. Bowen, I am filled with gratitude that you were my advisor along this journey. You walked side by side with me. You had my back when others did not, and most of all, you respected me.

Persimmon Blackridge, Psim, thank you for editing my work to help me improve my writing. I’m so glad that I could entertain you when you had a bummed-up leg.

Last but not least, to my mom, Jewelene Child, I am so grateful that our relationship has grown over the past several years. I appreciate you more than words can say.

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Chapter One: Introduction

Most people, including researchers, health professionals, educators, and others agree that there are certain skills largely based on vocabulary recognition, reading comprehension and numeracy that people need in order to take care of their health and have a meaningful life. This collection of skills is called *health literacy*. Health literacy grew out of the literacy field and was initially concerned with basic literacy skills of reading (vocabulary recognition, comprehension and numeracy skills). Ratzan and Parker (Selden et al., 2000) developed one of the earliest definitions of health literacy: “The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions,” (p. vi). This definition was used in *Healthy People 2010* and the Institute of Medicine’s (2004) landmark report, *Health Literacy: A Prescription to End Confusion*.

From the perspective of this thesis, the early definition fails to address that health literacy also involves interaction with health care providers. The increasingly complex healthcare system requires individuals to take a more active role in health care decisions and management more so than ever before (Martin & Parker, 2011). Health literacy is critical to successful access to care and use of health services, self-care of chronic conditions and maintenance of health and wellness.

Based on population studies, low health literacy affects 90 million people in the U.S. (Nielsen-Bohlman et al., 2004). Therefore, one can argue that limited health literacy is likely to impact most social work clients because most social work clients experience disadvantages, lack access to resources, experience health disparities, experience vulnerabilities due to mental health challenges and other disabilities, and/or are affected by long term use of substances, incarceration, abuse, or health challenges and structural oppression (Ayalon & Alvidrez, 2007; Sherraden et al., 2014, 2015; Uehara et al., 2014). Because essential components of health literacy are based on reading and writing, some social workers may believe that health literacy is outside the scope of social work's practice and more relevant to educators.

Additional factors that may have an effect on health literacy include a person's emotional state, how they process information, and timing of presentation of information after receiving a particular impactful diagnosis such as cancer or other diagnoses that impact a person's lifestyle (Joseph-Williams et al., 2014; McClain, 2012). People who have just had accidents may also struggle accessing their health literacy knowledge and skills due to shock or other worries. Social workers may be called upon to help the person emotionally process the diagnosis and answer other questions.

Cancer doctors (Bath-Hextall, et al., 2017) and other specialists who give diagnoses with potential huge life consequences often schedule two appointments—one where they present the diagnosis, and then a follow-up appointment to provide information about the person's specific condition giving a person a few days to process their diagnosis (in a non-crisis situation) and when immediate treatment will not impede the treatment response. Often times, people will bring a trusted, supportive person with them to accompany them when hearing difficult health news. While some mental health practitioners may encourage people to bring a caring, supportive person to an appointment, this is not a common practice in mental health. Given the stigma from others, one wonders why mental health providers have not used this strategy to help build social support for people who are diagnosed with mental illness?

This thesis seeks to understand health literacy among people diagnosed with mental illness from a social work perspective. From the social work vantage point, the thesis is particular focused upon understanding the person in relation to their broader environment. Social workers create opportunities for diversity and social justice using an anti-oppressive framework, by engaging with and assessing individuals, groups, organizations, and systems using diverse forms of evidence and knowledge. They design interventions with the goal of addressing preexisting and new problems as they arise. Social work researchers, scholars, and practitioners also use evaluation as a tool for continuously enhancing their understanding of key practices, programs, and policies.

In an effort to improve the quality of services delivery in complex health care systems, social workers are primed to aid in improving health literacy. Social workers in medical settings break down health literacy barriers in their daily practice with individuals and families through their roles as advocates, system navigators, allocators of resources, and medical system translators, etc. (Liechty, 2011). At a professional level, social work is well-suited to address health literacy through health promotion and structural activities (e.g., working with organizations and providers to use plain language, working with individuals, communities and groups to increase their health literacy knowledge). Specifically, social workers may increase equity and decrease health disparities, particularly when supported by an ecological framework (Haight & Taylor, 2006). Social work’s emphasis on a strengths-based approach to health literacy and its work to facilitate multiple approaches to building knowledge offers an alternative to the deficit-laden medical model (Hill, 2004).

Health Literacy and Health Outcomes

More than 90 million people (nearly half the adult population) lack the health literacy skills needed to understand and act on health information and health system demands in the U.S. In the most recent international literacy study (U.S. Department of Education National Center for Education Statistics, 2019 54% of adults have a literacy below 6th grade level. Only 12% of U.S. adults have health literacy proficiency to perform complex tasks, according to an Institute of Medicine (IOM) report (Nielsen-Bohlman et al., 2004.

People with low health literacy have poorer health outcomes than those with higher health literacy. For example, people with limited health literacy skills are less likely to use preventive health care services such as mammograms, Pap smears and flu shots compared to those with adequate literacy skills (Scott et al., 2002). Also, persons with limited health literacy skills have poorer health status than those with adequate health literacy skills and are more likely to have chronic conditions and have difficulty managing their conditions. Research has demonstrated that patients with high blood pressure (M. V Williams et al., 1998), diabetes (Baker et al., 1999; Schillinger et al., 2003, 2004), asthma (Rosas-Salazar et al., 2012) and HIV/AIDS (Kalichman et al., 1999, 2000, 2005) who have low health literacy skills have less knowledge about their health conditions and how to manage them.

Low health literacy is associated with an increase in preventable hospital visits and admissions (Baker et al., 1997, 1998; Gordon et al., 2002). Researchers have also found higher rates of hospitalization and use of emergency services (Baker et al., 1998), and hospital readmission within 30 days (Mitchell et al., 2012) among those with lower health literacy skills. In addition, people with lower health literacy use services designed to treat complications of disease more than they use services designed to prevent complications (Baker et al., 1998, 2002; Gordon et al., 2002; Scott et al., 2002). The higher use of health care services designed to treat complications of disease result in higher health care costs (Friedland, 1998; Howard et al., 2005). Some research suggests that people with lower health literacy skills also experience higher personal costs such as increased inpatient care charges (Weiss & Palmer, 2004).

People who are members of social and cultural groups that are not part of the dominant discourse (e.g., non-native English speakers, people with chronic health conditions, people with less education, older adults, people who are unemployed or uninsured) are at increased risk of lower health literacy (Kutner et al., 2006) and increased risk of shame and stigma. Shame and stigma often accompany low health literacy. Some people may seek to hide their problems with health care providers due to shame and embarrassment about not being able to read and write or understand what the health care provider is telling them—even appearing to agree when they disagree with or do not understand what the health care practitioner is telling them (Parikh et al., 1996).

For some people who don’t speak English as their first language, low literacy in their native language may also cause people to feel shamed (Baker et al., 1996). The idea of questioning a health care provider may go against an individual's cultural traditions and beliefs causing more shame or causing a person to agree in order to avoid discomfort, embarrassment and shame. Different world views and beliefs about causes of medical problems may also contribute to challenges with health literacy (Fadiman, 1997).

Health Literacy among People Diagnosed with Serious Mental Illness[1]

The only prevalence approximation of low health literacy among people with mental health challenges that I found in the literature was from a secondary analysis of the National Assessment of Adult Literacy (NAAL). Researchers confirmed that American adults 16 and over who reported having a mental health problem had significantly lower levels of general health literacy than adults who did not report a health literacy problem (Sentell & Shumway, 2003). This finding is likely an underestimation, as people with more serious mental health challenges were disproportionately excluded from the study. There are no other population estimates of low health literacy of people with mental health challenges.

People diagnosed with serious mental illness experience disparities in health care (Culhane-Pera et al., 2009; Desai et al., 2002; Felker et al., 1996; Jones, et al., 2008). People who are at risk for health disparities due to other social determinants of health (e.g., race/ethnicity and socioeconomic status) and who are diagnosed with mental illness face additional risk and burdens. Researchers have known for more than 50 years that in

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[1] I use several terms when referring to people diagnosed with serious mental illness. Because there is no commonly agreed upon terminology to reference ourselves. If there were a term that was more acceptable to my peers, I would use it. Thus, I choose to use different terms to refer to those of us who are diagnosed with serious mental illness.

high-income countries, the life expectancy of people with mental health challenges is significantly shorter than the general population without mental health challenges (Felker et al., 1996; R. C. W. Hall et al., 1981; Karasu et al., 1980; National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, 2006; Newman & Bland, 1991; Thornicroft, 2011; Thornicroft & Tansella, 2011.

Importantly, little research has been done to identify the role that low health literacy plays in the health care outcomes of people with mental health challenges. However, this thesis contends that people with mental health challenges need health literacy skills just like those without mental health challenges. Mental health symptomatology (e.g., hearing voices, anxiety, mania and/or depression) can often interfere with a person's reading comprehension, vocabulary recognition, numeracy skills and their ability to communicate with health care providers. People experiencing mental health symptomatology may have difficulty communicating their experiences and therefore, withhold needed information or provide information that is confusing to health care providers. As well, people experiencing mental health symptomatology may have difficulty understanding or accurately remembering what the health care provider tells them. Also, people may need information presented in different ways when they experience active symptomatology. People diagnosed with mental illness often have other co-occurring health conditions (e.g., poly-substance abuse, diabetes, chronic heart failure, high blood pressure) (Thornicroft, 2011). Many treatments for the co-occurring health conditions interact with the symptoms and treatments of the mental health conditions.

Evidence suggests that people with mental health challenges are at risk for low health literacy (see Chapter three for literature review). People using publicly funded mental health services face increased burdens when navigating our health care systems. Historically, publicly funded mental health care systems have operated separately from publicly funded physical health services. It has only been in the last few years that efforts have been made to integrate physical and behavioral health care for people who use publicly funded services. However, there is little documented effort to address health literacy for people who have mental health challenges in most of these integrated care efforts. Even for people who are able to access privately funded health care services, getting physicians and practitioners from different disciplines to communicate with each is often fraught with difficulty.

Why Is Health Literacy Important for People Diagnosed with Mental Illness?

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People with mental health challenges are frequently subject to treatment regimens that can include complex medication routines, advice about lifestyle factors (e.g., sleep, diet, exercise, daily routines and stress management) and the need to attend appointments with a range of clinicians (e.g., psychiatrists, nurse practitioners, case managers, therapists)—and this is just providers in the public mental health system. Medical illnesses frequently accompany the onset of psychiatric symptoms and can even be missed if all that is focused on is the psychiatric symptomatology. For example, Hall and colleagues (1982) identified nine categories of medical disorders that are known to cause psychiatric symptoms including diabetes, brain tumors and infectious diseases. Studies from the early 1990s found that Type II diabetes was a problem for people diagnosed with schizophrenia prior to the advent and large-scale use of atypical antipsychotics such as olanzapine (Zyprexa™) and risperidone (Risperdal™) (Dixon et al., 2000). Research has established a strong link between heart disease and depression and anxiety (Barefoot et al., 1996; Frasure-Smith, et. al, 1995; van Melle et al., 2004; Watkins et al., 2013). Rosenberg and colleagues (2001) found elevated rates of HIV, Hepatitis B (HEPB) and Hepatitis C (HEPC) in a prevalence study of people with severe mental illness. Given that HEPC frequently goes undetected even in people without severe mental illness, it would not be surprising to discover that people with severe mental illness are at higher risk for HEPC. Lack of early detection and appropriate treatment for HEPC will cause liver damage and the unknowingly transmission of HEPC to others.

The physical health care system historically has not interacted effectively with the behavioral health care, despite decades of research documenting that people diagnosed with severe mental illness have worse health outcomes as discussed above. Some reasons for this fragmentation include stigma and discrimination by health care practitioners and other medical personnel and Medicaid payment restrictions, which can make it difficult if not impossible to address an individual's physical and behavioral health in the same visit (Balsa & Mcguire, 2003; Garey, 2013; Happell et al., 2012; Harangozo et al., 2013;

Jones, et. al, 2008; Nash, 2013; Shefer et al., 2014; Sullivan, et. al, 2006; Thornicroft et al., 2007; van Nieuwenhuizen et al., 2013; Weisfeld & Perlman, 2005).

While the physical health care access and treatment difficulties are well documented, many mental health practitioners also have failed those who are diagnosed with mental illness in terms of addressing their physical health care needs. In my practice experience, I have seen mental health practitioners ignore or misattribute serious signs of physical illness to a person's mental illness. For example, a person eventually diagnosed with end-stage colon cancer was told several times by her psychiatrist that the pain and bowel problems she was having were a figment of her imagination and part of her mental illness that had been going on for more than a year, many people have expressed concern about the substantial weight gain (sometimes 50 pounds in two months) that was attributed to the psychotropic medication they recently started that contributed to metabolic syndrome—a combination of diabetes, high blood pressure, heart disease and obesity that is often directly attributable to taking neuroleptic medications).

Equally challenging but less frequently discussed is the issue of people not wanting their physician or health care team to know they struggle with literacy. In one study (Parikh et al., 1996) in an acute care setting, 67.2% of participants who had low health literacy and admitted having difficulty with reading had never told their spouses and 53.4% had never told their children. The shame that many people feel about their inability to read complicates the health care provider-patient relationship.

People diagnosed with serious mental illness can often have complex health needs; and they must navigate not one but two or more health care systems. Working across systems can complicate the ability of individual treatment providers to address the person’s stated desires and/or best interests. The behavioral health care system has traditionally been separated into mental health services and addiction services despite being administered by the same state and county agencies. For example, efforts to integrate the Addiction Division and the Mental Health Division within the Oregon Health Authority began about 15 years ago. Primary mental health and addiction service providers began augmenting their programs by hiring licensed clinicians who could provide treatment to people with co-occurring substance use and mental health disorders within the last 10-12 years. Prior to this, clients with co-occurring disorders faced a revolving treatment door; mental health providers would tell clients that they must get their addictions treated first before they could be served in a mental health agency and addiction providers would tell people with mental health disorders that they needed to get off all medication because it was part of an addiction. Given the level of service fragmentation, it is amazing that anyone was able to recover from either their addictions or mental health problems. Legislative and stakeholder efforts to improve systems drove the push for integrated behavioral health care services before the additional system reformation efforts of the Affordable Care Act of 2010 took effect.

Beresford (2003a) hypothesized that “The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable, and distorted” (p. 22). His hypothesis speaks to the importance of user/survivor knowledge and what is missing in health literacy research. There is a growing movement for lived experience research or “user involvement research” in health and social care (Beresford, 2007). Beresford also identifies three tiers of user involvement research: (a) ‘user involvement research’ in which people who use services are involved in the research process in the range of traditional approaches to research, (b) ‘collaborative research’ where service users and their organizations work in partnership with other researchers; and (c) ‘user research’ or lived experience research which is when people with lived experience develop and control their own research projects (p. 308).

Thus far, the health care problems that people diagnosed with severe mental illness face have been presented from the perspective of health care providers. Here, I discuss challenges that people with mental health diagnoses face from the service user perspective.

Andersen’s (Andersen, 1995; Andersen & Newman, 1973) model of access to healthcare services highlights individual and structural challenges to health care access at each point of access (e.g., diagnosis and treatment). This model can be usefully applied in the case of people diagnosed with serious mental illness. People diagnosed with mental illness have several issues and concerns about accessing, obtaining and using health care regardless of whether it is for physical health or behavioral health care.

Another reason that assessing health literacy and how one’s health literacy level impacts a person is that many mental health interventions use journaling as a treatment modality (e.g., cognitive behavioral therapy). People with low health literacy may find it difficult to journal which may limit the effectiveness of the treatment being proffered (A. K. Lincoln et al., 2008).

Diagnostic Overshadowing

The concept of diagnostic overshadowing concerns the existence of one diagnosis that alters the diagnostic and treatment recommendations resulting from another diagnosis (Goldsmith & Schloss, 1986). The term was first used in 1982 to refer to the tendency for clinicians to attribute symptoms or behaviors of people with learning or cognitive disabilities to their underlying cognitive deficits and to under-diagnose the presence of other co-occurring health conditions (Ross, Levitan & Szyszko (1982). Most of the literature around diagnostic overshadowing addresses people with intellectual disabilities. Curiously, while diagnostic overshadowing has not been discussed much in the psychiatric literature to date in the U.S. psychiatric literature, discussion has started in the UK and Australian psychiatric literature. Yet in my personal and practice experience, diagnostic and treatment overshadowing occurs often with people diagnosed with psychiatric disorders and disabilities and mirrors experiences discussed in (Clarke et al., 2007; Jones, et. al., 2008; Thornicroft et al., 2007).

Emergency Room Treatment

Stefan (2006) identified several problems that people with psychiatric disabilities encounter when seeking support from (or brought unwillingly) to emergency departments (EDs). Very often, people with psychiatric disabilities have different perspectives and ideas about the problems for which they are seeking treatment (or are being compelled to obtain treatment). The six primary categories of problems that people with psychiatric disabilities encounter in the ED include the use of force, the ignoring or minimizing of medical complaints, treating psychiatric emergencies with contempt or derision, delays in emergency room treatment, access issues for specific populations (e.g., deaf or hard-of-hearing patients), accompaniment while waiting and lack of effective grievance mechanisms or advocacy.

Clark and colleagues (2007) conducted focus groups with service users with a variety of diagnoses including psychotic and depressive illnesses, post-traumatic stress disorder, personality disorders and co-occurring substance use disorders. The researchers reported that several participants described difficulties when presenting to an emergency department (ED) for medical concerns. Participants "felt they were labelled and triaged as 'psychiatric' regardless of their complaint" (p. 128). Jones and colleagues (2008) argue that the term *treatment overshadowing* "include all components of a treatment plan that can be overlooked such as an unwillingness to address possible barriers to appropriate care" (p. 170). Hence, they suggest a combined term of *diagnostic and treatment overshadowing* when planning future research.

Iatrogenic Stigma

Iatrogenic stigma (Sartorius, 2002) is the stigma that occurs in mental healthcare. One of the more striking sources of stigmatization in healthcare is the casual and careless use of diagnostic labels. Iatrogenic stigma also serves as a way of controlling who gets access to services. Only people deemed to be worthy "or legitimately mentally ill" get access to certain services. If a person is viewed as not legitimately mentally ill, they can be ostracized or given a new label such as borderline personality disorder.

Stigmatization from Healthcare Professionals

Healthcare professionals outside of the psychiatric profession can stigmatize people diagnosed with mental illness. Healthcare professionals may experience fear, negative attitudes, poor understanding of mental health conditions and what it is like to live with such conditions, and emotional difficulty with patient interaction (Silva et al., 2015). In other words, many healthcare professionals may believe that talking with someone with a psychiatric disorder is difficult and that people with psychiatric disorders are dangerous and unpredictable. Also, many healthcare professionals may believe that once one is diagnosed with a psychiatric disorder, there is much pessimism about one’s prognosis and future. Healthcare professionals’ stigmatizing beliefs may have several repercussions for their patients diagnosed with mental illness (Silva et al., 2015):

- Multiple barriers for help-seeking and care;
- Diagnostic overshadowing;
- Under-diagnosis and under-treatment;
- Treatment delay and development of complications;
- Higher rates of mortality and morbidity due to physical illness; and
- Negative impact on patient quality of life

The Urgency of Addressing Health Literacy

Federal Policy Efforts

Several federal policy initiatives in the past decade have led to the increased sense of urgency to improve health literacy in the United States. The U. S. Congress passed two statutes in 2010 that addressed health literacy: The Plain Writing Act (2010) and the

Affordable Care Act (2008). The purpose of the Plain Writing Act of 2010 “is to improve the effectiveness and accountability of Federal agencies to the public by promoting clear Government communication that the public can understand and use.” President Obama issued Executive Order 13563 (“Executive Order 13563,” 2011) stating that [our regulatory system] “must ensure that regulations are accessible, consistent, written in plain language, and easy to understand." Two additional Executive Orders cover the use of plain language in government regulations (*Executive Order 12866*, 1993; *Executive Order 12988*, 1996).

The Patient Protection and Affordable Care Act (2010) (PPACA) commonly referred to as “Obamacare”, or the “ACA”, directly references health literacy four times in the statute. Section 3501 requires that the Agency for Healthcare Research and Quality (AHRQ) be accessible to the public; and the AHRQ’s public programs and documents should “reflect varying needs of providers and consumers and diverse levels of health literacy” (J(d)(1)d). Section 3506 requires that “Decision aids must reflect varying needs of consumers and diverse levels of health literacy.” Section 3507 of the PPACA requires the Secretary of the Department of Health and Human Services to “consult with…experts in health literacy”. Section 5301 provides for “preferences for training grants in cultural competence and health literacy.”

Also, there are several indirect references to health literacy in the PPACA (2010) in six domains: (1) Insurance reform, outreach and enrollment, (2) individual protections, (3) equity in special populations and workforce development, (4) health information, (5) public health, promotion and prevention and wellness; and (6) innovations in quality and delivery and costs of care. Finally, Martin and Parker (2011) compellingly argue

> “The ongoing evolution of the health care system is leading US households toward greater responsibility for their own well-being. With this responsibility, however, comes an increasing need to be able to find, trust, use and act on relevant information to make informed choices. Yet there continues to be a substantial mismatch between the high literacy burden of health information materials designed to support such choices and the health and financial literacy skills of individuals who use them,” (p. 874).

State Policy Efforts

The State of Oregon passed its landmark health reform legislation in 2011. In particular, SB 3650 which moved from managed health care to coordinated care organizations promising person-centered medicine, with the triple aim (Berwick et al., 2008) of “improving the individual experience of health care, improving the health of populations, and reducing the per capita cost of health care,” (p. 760). However, the bill failed to make mention of health literacy in its 40 pages.

The Legacy Hospital System located in the Portland metropolitan area has recognized that inadequate health literacy creates significant barriers for people in addition to raising the cost of health care. It has sponsored a regional conference on health literacy for the past few years (prior to the Covid-19 epidemic) of which the Oregon Health Authority has been a cosponsor (Legacy Health, 2014). However, there are no state-wide efforts to address health literacy despite the costs associated with inadequate health literacy.

Economic Costs of Poor Health Literacy

Eichler, Wieser, and Brügger, (2009) conducted a systematic review on the cost-effectiveness of health literacy interventions. Eichler found that at the health system level, the additional costs of limited health literacy vary between three and five per cent of the total health care cost per year. At the patient level, the additional expenditures per year per person with limited health literacy as compared to a person with adequate health literacy range from $143 to $7,798. It should be noted that out of nearly 2500 scholarly and research papers pulled for review, only 10 met the study inclusion criteria. Some smaller studies focusing on economic costs of health literacy found similar results as Eichler (Hardie, Kyanko, Busch, Losasso, & Levin, 2011; Howard et al., 2005; Weiss & Palmer, 2004).

Research Questions Guiding this Study

The following research questions guide the proposed study: According to people diagnosed with serious mental illness and who use publicly funded health care

- What are the health literacy needs of people diagnosed with mental illness in physical and behavioral health?
- What are the barriers and facilitators of health literacy?
- How does health literacy impact people with psychiatric disabilities in physical and behavioral healthcare? and
- How can healthcare providers (physical and behavioral) address the health literacy needs of people with psychiatric disabilities?

These questions are intended to support empirical studies that asks people how low health literacy impacts them and how they navigate the health care systems despite having low health literacy. The questions also support the value that people are the best experts on their own lives regardless of their perceived deficits. Also, the literature to date has not clearly addressed the possible changes in health literacy or the need for different types of information when people are experiencing emotional distress or symptomatology. Who else would be better to ask about their needs than service users who consent to being research participants?

In summary, inadequate health literacy is a major social problem that affects more than 90 million people in the US. Little is known about health literacy among people diagnosed with mental illness who use publicly funded mental health services. At the same time current policy directives directly or indirectly require health care workers, administrators and others to address the health literacy needs in order to provide person-centered care.

Chapter two provides a more comprehensive review of the literature specific to health literacy and people diagnosed with mental illness. Chapter three of this proposal explains my theoretical framework and approach to my research question. Chapter four details the study methods and procedures. Specifically, an exploratory study used focus groups and one individual interview in tandem with a small quantitative survey. Chapter five presents the results of the study, and Chapter six provides a discussion of key findings, study limitations, and implications for social work research, practice, and policy.

Chapter Two: Literature Review

Chapter two reviews the literature relevant to general health literacy of people who use publicly funded mental health services in both behavioral and physical health care. This critical review focuses primarily on research outcomes and to a lesser extent research methods. The literature in this review includes pivotal or seminal pieces with two exceptions. The bodies of literature that discuss the intersections of health literacy with health literacy in social work and health literacy with people diagnosed with mental illness are small. Therefore, these sections of the literature review will be exhaustive.

Given that these two bodies of literature are small, these sections are organized using a historical perspective so as to demonstrate some of the social aspects that have changed over time. The intended audiences for this review include practitioners, policymakers and people who use publicly funded mental health services.

Typically, in a user-survivor literature review, one would include gray literature from users and survivors (Fleischmann, 2009). However, general health literacy is not an issue that has been addressed directly by other user/survivor researchers, although the closely related concerns of informed consent, decision-making and talking with one's doctor have been issues that people who use publicly funded mental health services have expressed concern and distress for decades if not centuries (Beers, 1923; Chamberlin, 1979; Deegan, 1996, 2010; Stein et al., 2013).

Search terms used in multiple databases (e.g., Google Scholar, Social Services Abstracts, CINAHL, and Medline) included the following terms: *health literacy* combined with *mental illness*, or *psychiatric*, or *schizophrenia*, *bipolar*, *depression*. It should be noted that I excluded the term *mental health literacy* (Jorm et al., 1997) because its definition and operationalization are narrower and directed at the lay public, not the individual person who uses publicly funded mental health services. While mental health literacy is an important issue to address, it is not the focus of this literature review.

Health Literacy as a Changing Social Construct

Health literacy as a construct evolved over time as educators defined, redefined and quantified the functional literacy needs of adults (Berkman et al., 2010). Baker (2006) acknowledged the lack of consensus on the meaning of *health literacy* among researchers and others with related expertise despite the field's rapid growth. Even with a landmark report from the (Institute of Medicine, 2004), Baker's goal of adopting a shared definition of health literacy has not yet occurred. Health literacy as a construct evolved out of the changing understanding of literacy.

Literacy

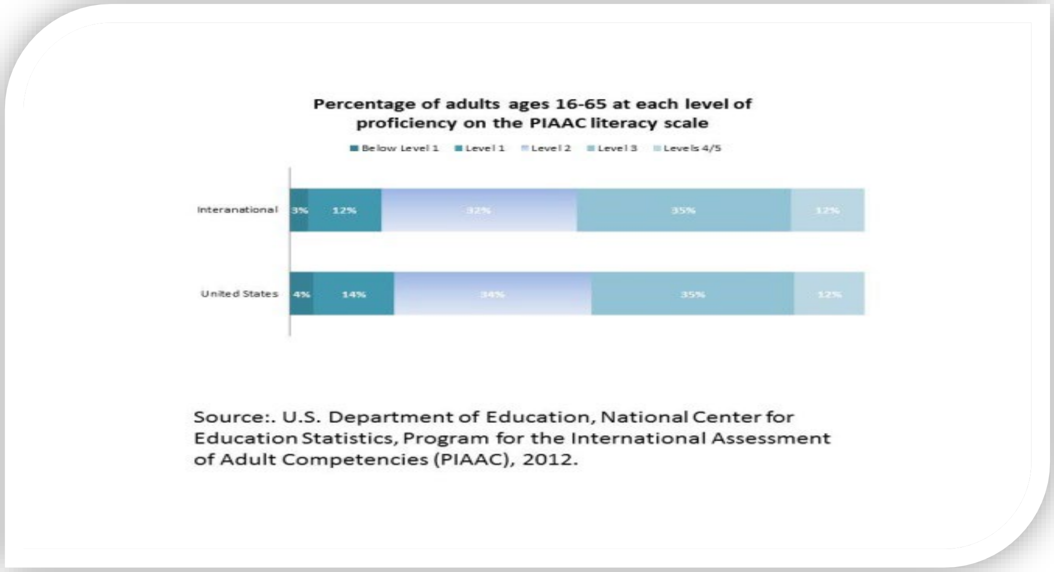
The definition of literacy has changed over time. Before the Civil War, an individual was considered literate if they could sign their name instead of marking with an X (Lockridge, 1974). During the mid-1800s until the 1930s, the U. S. Census Bureau asked individuals (mostly white males, at first) if they could read and write in any language. Using this method, 20% of the U.S. population was deemed illiterate. By 1979, only .6% of adults reported being unable to read or write using this same definition (Kaestle et al., 1991).

The Department of Education commissioned the National Adult Literacy Survey (NALS) to assess the depth and breadth of adult literacy in the entire population (Kirsch, et al., 1993a). Subsequently, the Department of Education conducted the National

Assessment of Adult Literacy Survey (NAAL) in 2003, which aimed to identify how many individuals had *below basic* skills and needed basic education (Kutner et al., 2006). Health services researchers and *Healthy People 2010* requested that health items be included in the survey (Berkman et al., 2010). The NAAL was the first population-based survey to include a component specifically designed to measure health literacy in U.S. adults living in the community and adults incarcerated in prison.

Figure 1

Percentage of Adults at Each Level of Proficiency on PIAAC Literacy Scale



Source:. U.S. Department of Education, National Center for Education Statistics, Program for the International Assessment of Adult Competencies (PIAAC), 2012.

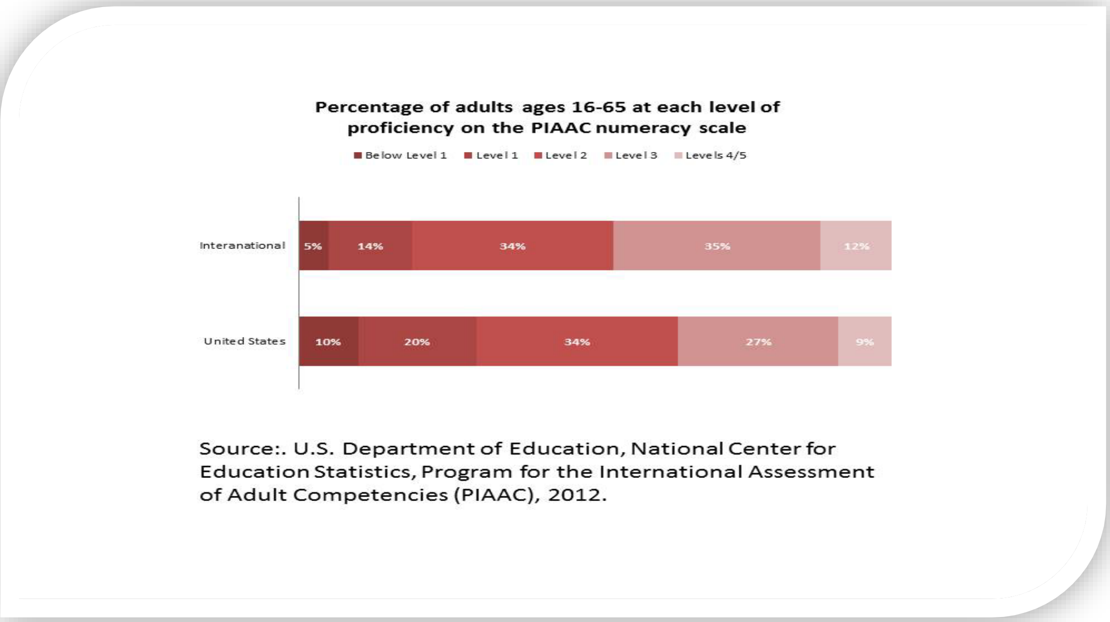
Figure 1: Percentage of Adults at Each Level of Proficiency on PIAAC Literacy Scale

Literacy in the 21st Century

The Program for the International Assessment of Adult Competencies (PIAAC) developed and conducted a household survey under the auspices of the Organization of Economic Cooperation and Development (OECD). The PIAAC assesses cognitive skills in the areas of literacy, numeracy and problem solving in technology-rich environments. 23 countries along with the United States participated in Round 1 of the study. More than 165,000 working-age adults representing more than 724 million adults in 21 countries participated in the first round of the PIAAC. The U.S. obtained a nationally representative sample of 5,000 adults between the ages of 16 and 35 (see Figures 1-2) (PIAAC, 2014).

Figure 2

Percentage of Adults at Each level of Proficiency on the PIAAC Numeracy Scale



Percentage of adults ages 16-65 at each level of proficiency on the PIAAC numeracy scale

Source:. U.S. Department of Education, National Center for Education Statistics, Program for the International Assessment of Adult Competencies (PIAAC), 2012.

Figure 2: Percentage of Adults at Each level of Proficiency on the PIAAC Numeracy Scale

This short history of literacy in the United States demonstrates that as the economy shifted from an agrarian economy to an industrial economy, and now an informational economy, the understanding of literacy also shifted and evolved. Defining and measuring literacy has grown more refined and changed to meet the complex demands of life and function successfully in today's world (Berkman et al., 2010). Researchers have clearly documented the relationship between literacy, health status and health outcomes over the past 20 years (Berkman et al., 2010; DeWalt et al., 2004; Institute of Medicine, 2004).

Health Literacy

As a relatively new construct, health literacy has multiple definitions and has not been consistently applied (Berkman et al., 2010). Educational attainment is often used in health and health-related research as a proxy measure of health literacy. As such, it is highly problematic. Individuals with similar educational attainment can have a wide range of skills in reading, analysis and mathematics (DeWalt et al., 2004; Kirsch et al., 1993b; Kutner et al., 2007; TenHave et al., 1997).

Research Conceptualizing and Operationalizing Health Literacy

Health literacy is a complex term to define, operationalize and measure because multiple skills (e.g., reading, reading comprehension, vocabulary, writing, communication, numeracy, critical analysis, decision-making and acting on information) are required to be health literate (Baker, 2006; Dray & Papen, 2004; Jordan et al., 2011). Likewise, the contexts in which people apply these skills are diverse. For example, completing patient questionnaires or figuring out the correct dosage of medication requires different skills than talking with one's doctor about a new diagnosis or a follow-up appointment for a long-term condition. Another reason health literacy is difficult to measure is that the skills required to interact with the health care system evolve and change over time. As technology evolves and changes the ways in which people interact with the health care system, the definition of health literacy will need to evolve as well.

In a structured literature review Sørensen and colleagues (2012) identified 17 health literacy definitions and 12 conceptual models, condensed into six clusters. These six clusters include (1) competencies/ skills/abilities, (2) action(s), (3) information, (4) objective(s), (5) context, and (6) time. How researchers measure health literacy and the instruments used to measure health literacy will be discussed subsequently.

A researcher from Australia (Nutbeam, 2008) contends that the different models and definitions of health literacy can be synthesized into two co-existing and valid definitions. The clinical perspective views health literacy as a risk-management issue. The public health perspective views health literacy as a skill-based personal asset. (Chinn, 2011) examines the concept of critical health literacy in response to the criticism that the plethora of definitions and conceptual models have “overstretched the concept of ‘literacy’ and simply puts ‘old wine in new bottles’ by recycling health promotion concepts such as ‘empowerment’ and ‘patient involvement’ (Tones, 2002; Willis, 2009) which themselves remain somewhat contested and open to multiple interpretations” (Chinn 2011, p. 60).

Viewing health literacy through a social work practice lens, requires that we incorporate the methods patients use to conduct information-seeking activities (verbal and text-based) and the person-in-environment perspective. According to (Dray & Papen, 2004) “Patients’ own information seeking practices, their actions and reactions towards information, are central to understanding people’s involvement in their own healthcare”

(p. 314). The importance of this emphasis on the patient's perspective is supported by the lack of knowledge of patients' strategies in current research, as reflected in the National Consumer Council's (2004) research on health literacy. (Dray & Papen, 2004) also identified the need to examine more closely the status that such strategies (and the knowledge that emerges from them) have – or have not – in the institutional domain. This section summarizes some key definitions and concepts of health literacy. The Institute of Medicine (IOM) (2004) defined health literacy as "the individual's capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions." This definition is frequently cited and used in numerous studies (Sørensen, et al., 2012).

In an updated review of the literature (Malloy-Weir et al., 2016) researchers identified more than 250 definitions of health literacy. They characterized the definitions into three categories: a) the most commonly used definitions (n = 6), b) variations of the six most commonly used definitions (n = 113), and c) other definitions (n = 133).

Other researchers use conceptual models to define health literacy. One of the more popular definitions using conceptual models is (Nutbeam, 2000). Nutbeam discusses public health literacy and multiple dimensions of health literacy such as functional (basic), interactive (communicative) and critical health literacy in which more complex analytical skills are required to evaluate information and make decisions about one's health and health care.

As discussed earlier, many researchers view literacy and health literacy as a set of skills. This skill-based understanding of literacy and health literacy also underlies much of the extant policies and research. (Dray & Papen, 2004) critiqued this view as follows:

> “Taking a ‘skills’ view of literacy assumes an overly simplistic view of communication whereby ‘reading’ and ‘understanding’ are often implicitly assumed to be one and the same thing. Skills views of literacy, and this is particularly important for the health care context, also tend to assume a direct link between a patient’s understanding of a text and their willingness to act upon it” (pp. 313-314).

Dray and Papen (2004) argue that health literacy is more than abstract skills. They state “It is more appropriate to think of health literacy (i.e. the practices and social relationships around written health texts) as being situated within institutional structures, which both shape and are shaped by each other” (p. 314). Dray and Papen suggest that in understanding how patients react to health information and its ‘usefulness’ in terms of providing health care and restoring the patient’s well-being, one must consider how the written language of health information constructs social identities (Fairclough, 1992).

Dray and Papen (2004) assert that rather than privileging the processes of how written language is decoded and encoded, researchers need to understand that health literacy is a multidimensional concept requiring the researcher to examine how particular texts are used in a health care event. Researchers must focus on the role the texts play in interactions between practitioners and patients as well as in institutional processes Dray and Papen further state that researchers need to find out which representations of a disease or disorder a particular text supports and how the surrounding institutional practices invite specific roles and behaviors.

While Dray and Papen (2004) do not specifically mention mental health challenges in their article, their concerns align with those of many service users/survivors of mental health services. For example, part of the recovery experience for many service users/survivors is re-storying (Ridgway, 2001) their lived experience—vis-à-vis the illness narrative they were told by providers, the mental health system and society.

Sørensen and colleagues (2012) grouped health literacy skills and competencies by the objectives of the skills (e.g. to improve health, make informed decisions) and the context or location of where and how the skills are used, as well as by tasks involved (e.g. seeking information, taking action) and evolution throughout the subject's lifespan.

Figure 3

Sørensen et al. (2012) Integrated Model of Health Literacy

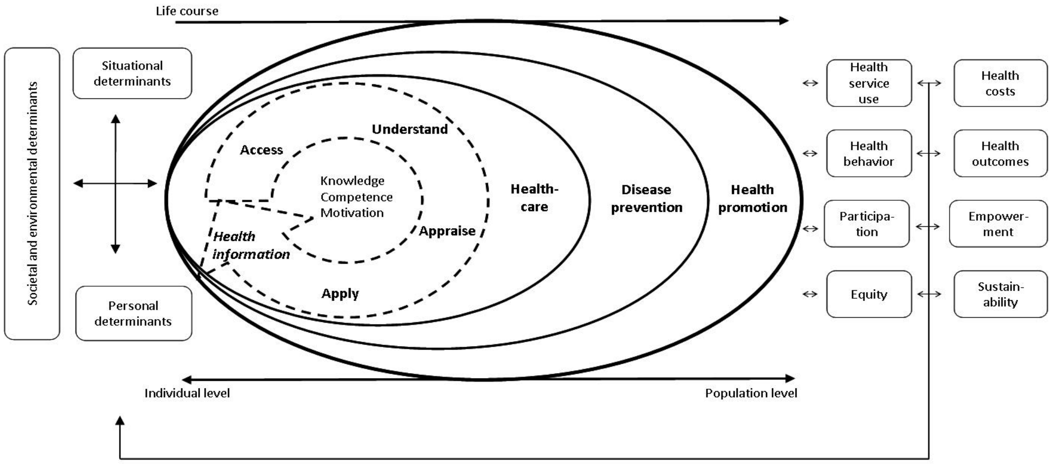


Figure 3:Sørensen et al. (2012) Integrated Model of Health Literacy

The conceptual framework proposed by Sørensen and her colleagues (2012) conceptual framework offers several improvements over previous definitions. For example, they view health literacy as essential throughout the life-course. They also include individual, social, and structural determinants (e.g., one's previous experience(s) with the health care system, health disparities), and the multiple tasks involved (which include accessing, understanding, appraising and applying health information that impacts health service use, health costs, health behaviors, health outcomes, participation, empowerment or the lack thereof, equity and sustainability). There is also an implication of the interaction effects of experience/history on health literacy. For example, as one gains experience and knowledge about a specific health condition, theoretically, one's health literacy would increase. Important issues that Sørensen's framework does not address include the role of ambivalence about medical treatments, and how health literacy is impacted when someone experiences extreme stress—such as when they are symptomatic with mental illness, and/or dealing with interpersonal violence or other types of trauma.

Finally, it should be noted that a recently published article that reviewed health literacy definitions (Malloy-Weir et al., 2016). Malloy-Weir and her colleagues identified 250 definitions of health literacy. They categorized the definitions into three categories: (1) Most commonly used definitions (n = 6); (2) modified versions of the most commonly used definitions (n = 133); and "other" definitions (n = 111). The researchers found that the most commonly used definitions were open to multiple interpretations and reflected underlying assumptions that were not always justifiable. They argue that attention is needed concerning how differing definitions and interpretation of health literacy may affect patient care and the delivery of health-related policy initiatives.

Measuring Health Literacy

Haun and colleagues (2014) inventoried existing health literacy instruments. They provided a descriptive review of the psychometric properties and conceptual methods of the 51 tools they identified in their search. Of the 51 tools that Haun and her colleagues identified, 26 measured general health literacy while 15 were disease-specific and 10 focused on specific populations. The researchers found that most tools were performance-based, required in-person administration and were exclusively available in a pencil-and-paper testing mode. Tools used proxy measures or measured nine of the eleven defined dimensions of health literacy. Reported administration times varied between 1 and 60 minutes. Most tools had limited validation procedures primarily due to inadequate power to ensure reliability across subgroups (e.g., age, gender, race/ethnicity). According to Haun's review, most tools lack key psychometric properties.

One instrument measuring health literacy not included in the Jordan et al., (2011) article was The Newest Vital Sign (NVS) (Weiss et al., 2005). The NVS falls under Jordan's and colleagues' (2011) assessment of direct testing of an individual's abilities, using a food label as the primary stimulus. Unlike the more common indices (e.g., the REALM), rather than measuring word recognition, the NVS attempts to use actual health literacy tasks as a brief measurement of health literacy that could be used in a clinical setting.

Researchers (Osborne, et al., 2013) used a validity-driven approach (Buchbinder et al., 2011) to develop the Health Literacy Questionnaire (HLQ). The HLQ addresses nine distinct areas of health literacy (see Table 1), creating one of the few tools that addresses the multiple dimensions of health literacy.

Table 1

Areas of Health Literacy Addressed by the HLQ

- Feeling understood and supported by health care providers
- Having sufficient information to manage my health
- Actively managing my health
- Social support for health
- Appraisal of health information
- Ability to actively engage with health care providers
- Navigating the health care system
- Ability to find good health information
- Understand health information well enough to know what to do

Table 1: Areas of Health Literacy Addressed by the HLQ

There is much dialogue occurring in the health literacy literature about the challenges of developing health literacy instruments that work well in different settings. Many health literacy instruments can be resource-intensive and require between 3-12 minutes to administer, which makes it less likely for them to be used in clinical settings where time is a perceived factor in managing the cost of care. (Wallston et al., 2013) tested the psychometric properties of the Brief Health Literacy Screen (Chew et al., 2008) designed for use in clinical settings. The BHLS' Cronbach's alphas were .80 for hospital patients (n=498) and .76 (n=295) for patients in clinical settings. When administered by a registered nurse the BHLS' scores were significant predictors of the short form of the Test of Functional Health Literacy (S-TOFHLA) after adjusting for age, education, gender and race. Thus, the BHLS demonstrated adequate reliability and validity as a tool for a measuring health literacy.

Advocating for the Health Literacy Needs of People with Mental Health Challenges

One researcher (Flaskerud, 2012) discussed the need for primary care providers to have mental health literacy so that they can recognize people presenting with mental health challenges in their practices and provide appropriate treatment. She noted that many providers perpetuate the stigma and discrimination that people with mental health challenges encounters in the process of receiving health care. Research is increasingly linking mental health and physical health care status (e.g., depression as a factor in heart disease (Gazmararian et al., 2000).

Fetter (2009) implored health literacy researchers to address health literacy needs of people who are homeless. She noted that homeless people include not just people living in shelters but also those staying in public transportation facilities (e.g., bus shelters, subway stations and other places). She also discussed how people who are homeless may also have young and school-age children who add to their need for health literacy skills. Fetter also remarked that little is known about the health literacy needs of people who are homeless, with only two studies exploring the health literacy needs of people who are homeless (Christensen & Grace, 1999; Sleath et al., 2006). See Chapter three for more discussion on health literacy and people who are homeless.

Researchers in Ottawa, Quebec (Farrell et al., 2020) conducted a study in a sample of persons diagnosed with mental illness served by three models of psychiatric support (Outreach, Assertive Community Treatment and Step-Down). The sample consisted of 192 clients amongst the three programs. Nearly half of the participants scored themselves as reading “very well”. When assessed using the REALM, more than three quarters (76%) were assessed as having a health literacy level of high school equivalence. Nearly 24% scored reading at a seventh-eighth grade level or less. Key recommendations from this study include treating people with respect, building literacy into intake practices, using multiple means of delivering information, and enhance individual communication techniques such as using teach-back, and using plain language.

Lincoln and colleagues (2013) expressed concern that the words used on both the Test of Functional Health Literacy (TOFHLA) (Parker et al., 1995) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) (common health literacy assessment instruments) had the potential to trigger and cause discomfort for people who have experienced sexual assault, abuse, neglect and other forms of trauma. Lincoln and her team argued that given the high prevalence of traumatic experiences in those diagnosed with serious mental illness (Kessler et al., 1995; Solomon & Davidson, 1997) health literacy assessments should be trauma informed. For example, on the REALM instrument, Lincoln’s team changed one of the words from *incest* to *ingest*. While Lincoln and her team ultimately chose not to use the REALM, they also recommended changing the word *rectal* to *renal*. They encouraged other researchers to review instruments in terms of the potential impact that a triggering event could have.

It should be noted that post-traumatic stress disorder (PTSD) is not limited to individuals with severe mental health diagnoses; nor are traumatic experiences limited to just those with a diagnosis of PTSD. While adjusting the S-TOFHLA for Lincoln’s et al.,

(2013) study seems reasonable, it does present the researchers with a dilemma of not having a validated instrument or creating a research environment that avoids unnecessary triggers. The researchers believed that what they lost in validation pales in comparison with what they gained in creating a research environment that avoids unnecessary triggers and respects the dignity of the people who are willing to participate in their research.

Health Literacy and Social Work

I conducted a literature search using the terms *health literacy* and *social work*. I excluded the term *mental health literacy* because it is a different social construct and is narrower in its meaning than the term *health literacy*. My literature search mirrored (Liechty, 2011) methods and yielded similar results.

My search resulted in only one article that addressed attributes of a health literate organization. Social work's attention to micro, mezzo and macro levels of ecological approaches to social problems would seem to be an area in health literacy that would benefit from social work scholarship. Based on list-serv discussions, more work is being done in terms of making organizations more health literate; yet there are very few published articles that address health literate organizations. Findlay (2015) discusses how social workers are well positioned to participate in advisory boards and interdisciplinary teams at the organizational, local, state and national levels. Since social work programs emphasize the interaction of micro and macro forces, social workers are prepared to use their tools to help remedy barriers to health and engage with communities and groups to reverse negative health outcomes through health promoting activities. Findlay also reminds social workers that health literacy interventions affect health outcomes at three essential points: (a) access to health care; (b) the interaction between clients and their providers; and (c) self-care (Paasche-Orlow & Wolf, 2007a).

Social Work's Influence in Health Literacy

Social Work Scholarship

Although medical social workers have a strong presence in breaking down health literacy barriers for their clients, social work research is largely absent in the field of health literacy. However, social work scholarship is present in closely related fields such as patient education, information seeking and patient navigation—which one might argue are aspects of health literacy (Liechty, 2011). Yet, current social work scholars appear not to use the terminology of health literacy. Are social work and our clients missing opportunities to align our concerns with patients and families and quality of care with institutional and national priorities (Liechty, 2011)?

The consequences of failing to use the term "health literacy" means missing out on opportunities to align our concerns about our patients and clients with others who are equally concerned about patient care and the experience of care—losing out on collaborative advocacy opportunities to partner at the local, state and national levels, and advance funding and programmatic opportunities (Liechty, 2011). Ultimately, it means missing out on opportunities to develop social justice, increase equity and decrease inequity.

Limited health literacy impacts most social work clients, who may experience multiple disadvantages including the lack of access to resources, language challenges such as non-native English speakers, experience of health disparities, and vulnerabilities due to mental health challenges and other disabilities, and increased risk for long term use of substances, incarceration, abuse, or health challenges and structural oppression (MacLeod et al., 2017a, 2017b; Nguyen et al., 2015; Rikard et al., 2016a, 2016b; Schaffler et al., 2018a, 2018b; Serper et al., 2014; Soto Mas & Jacobson, 2019; Ylitalo et al., 2018). Social workers know that many of the systems and bureaucracies' society has created are challenging to navigate even for people who are well-educated and have few barriers in life. In addition, health literacy impacts people throughout the lifespan. Because essential components of health literacy are based on reading and writing, some social workers may believe that health literacy is outside the scope of social work's fields practice and is more germane to educators. However, this view of health literacy is narrow and may be ethically fallible.

In sum, social work scholarship has a too small footprint in acknowledging, identifying, remedying or mitigating health literacy, particularly as compared to the considerable need for health literacy among uses of social work services.

One social work researcher (Findlay, 2015) argued that at the macro level, social workers can advocate for policy changes at the local, state and national levels in order to change practices related to health literacy. Linking social and legislative policies to encourage interaction among researchers, clients, health care practitioners and policymakers can create better policies. Not only is this expected through the Affordable Care Act and person-centered care—or better, person-directed medicine, it is crucial to increase health equity across all populations. In essence, health literacy can not only save and prolong lives, but it can also save money and enhance the quality of life of social work clients, their families and our communities (Findlay, 2015).

At the micro level, social workers can develop interventions that focus on the client and/or the organization. At the client level, interventions can be developed that use “teach back” techniques, where clients are asked to teach the social worker or other health care practitioner what they were just told. Other interventions could focus on assisting clients to develop tools to empower themselves (e.g., how to set an agenda for their doctor’s appointment to get their needs met). Still other interventions could focus on the needs of families and caregivers in supporting their loved ones (Findlay, 2015).

At the organization level, social workers can work with organizations to simplify the reading level of patient information—while appreciating that different styles of information may be needed to convey the same information to make it accessible for all. Social workers can work with their organizations to make literature jargon free and make it available in alternate formats (e.g., large print, braille, CD, video, transcripts and sign language interpretation for people who are deaf and hard-of-hearing). Social work has much to offer the health literacy field. Social work research is largely absent in the scholarship of health literacy, reflecting missed opportunities (Liechty, 2011). Yet alleviation of poor health literacy is congruent with social work values and has relevance at the micro, mezzo and macro levels. Many medical social workers engage in breaking through health literacy barriers with patients, families, communities and organizations in their practices every day. Social workers regularly publish research in the closely related fields of health promotion, patient navigation, information seeking, patient education and empowerment. So why aren't social workers using the term "health literacy"?

Six articles (Albino et al., 2014; Dastjerdi, 2012; Merry et al., 2011; Usher, 2011; Wong & Poon, 2010; Zanchetta et al., 2014) were not included in this review because they applied to populations outside of the U.S. No articles addressed structural or organizational issues of health literacy from a social work perspective. However, only one publication addressed organizational health literacy issues (Brach et al., 2012). Howard Koh (2013), who worked in the Obama Administration in the Office of the Assistant to the Secretary of Health and several colleagues, published an editorial that addresses structural and systemic issues of health literacy. Based on email list-serv conversations, macro level health literacy concerns are of increasing interest in the field. Again, social work scholarship is largely absent from this discussion, with other disciplines taking the lead.

Another interesting observation I made in reviewing the health literacy literature is how rarely health literacy researchers actually spoke with people who used health services unless they were designing a new instrument to assess health literacy (Jordan et al., 2010; Weiss et al., 2005). Findley (2015a) also expressed a similar concern about the lack of talking with people and understanding how they interact with health literacy in their everyday lives.

In the course of updating this literature review, I found only two new articles when using the search terms "health literacy" and "social work". One article (Calvo, 2014) focused its attention on health literacy among Latino immigrants in the U.S. The other article examined low health literacy in older adults (Findley, 2015). There is still a great need for social work to contribute to health literacy research especially when using the person-in-environment framework

One of the fundamental values of disability communities and to people who identify as users/survivors of the mental health systems throughout the world is “nothing about us without us!” People diagnosed with mental health disorders were not asked their opinion about these definitions or even if they are relevant to our lives. The lack of literature that examines health literacy from the perspective of the people it impacts was initially surprising. However, considering that most of the research is viewed from the lens of medical practitioners and medical researchers, the surprise quickly changed to an all-too-familiar frustration. Very little health literacy literature has asked people with low or inadequate health literacy about their view of having low or inadequate health literacy, or their recommendations for ameliorating or remedying inadequate health literacy. This is a substantive gap in the literature and requires more research.

As a result of this literature review, the researcher refined her thinking about health literacy as a construct. Health literacy is commonly viewed as an individual trait. Yet, some researchers have recognized the complexity involved in health literacy research and have broadened their perspective. Subsequently, the definitions of health literacy have expanded also.

In order to advance health literacy research, some researchers (McCormack et al., 2017) began shifting the focus away from patient-level skills and deficits to include not only individuals and populations but health professionals and health systems.

McCormack and her colleagues proposed a social ecological model to health literacy and patient engagement. First, McCormack and her colleagues argue that patient engagement and health literacy inform each other at the individual level. Secondly, McCormack conceived the layers of the social ecological model as reflecting the individual, the interpersonal, the organizational, community, and the macro or policy level. McCormack and her colleagues further acknowledged that the health literacy field may be struggling because of a lack of theoretical guidance on how to design multilevel interventions. While I am still thinking about the ramifications of this health literacy social ecological model, it is much more appealing than understanding health literacy as an individual and static trait.

Health Literacy of People Diagnosed with Mental Health Challenges

A historical review of health literacy and people with mental health challenges is of limited use at the present time because the body of literature is so small. Instead the research chose to review the literature in this section by sub-populations and/or co-morbid health conditions.

People Living in State Hospitals

Three of the earliest studies (Berg & Hammitt, 1980; Christensen & Grace, 1999; Coles, Roth, & Pollack, 1978; Klinge & Dorsey, 1993) tested literacy of patients in state psychiatric hospitals (see Table 2). These studies took place before the development of the health literacy construct.

Three of the earliest studies (Berg & Hammitt, 1980; Christensen & Grace, 1999; Coles, Roth, & Pollack, 1978; Klinge & Dorsey, 1993) tested literacy of patients in state

psychiatric hospitals (see Table 2). These studies took place before the development of the health literacy construct.

Table 2

Health Literacy Studies of People in State Hospitals

Study Name	Sample Description & Size	Findings
(Berg & Hammitt, 1980)	100 patients admitted consecutively to a state psychiatric hospital.	• The majority of patients were functionally illiterate in reading comprehension skills • Education background corresponded to word recognition skills but not reading comprehension • Literacy demands placed on psychiatric inpatients probably far exceeds their literacy skills
(Coles et al., 1978)	48 patients (15 female and 33 male) who had cumulative hospitalizations for at least two years and had been a patient for at least six months at the time of the study 42 patients with primary diagnosis of schizophrenia. Remaining patients had primary diagnoses of chronic brain syndrome, manic depressive psychosis, seizure disorders & psychotic reaction, alcoholism and mental retardation	• 25% scored below the first-grade level on the ABLE (University of Texas, 1976). 50% performed at the fourth-grade level or below. 23% scored between the fifth- and seventh- grade levels and 27% performed at the eighth-grade level or above • Median ABLE grade-level achievement was 5.8 • 37% of patients were classified as mentally retarded. Further analysis of those so labeled shows that 9 scored below the first-grade level on the ABLE, 4 were between the second- and fourth-grade level, and the remaining 5 were at fifth-grade level or above • IQ tests were not routinely administered but only ordered after the physician arrived at a tentative diagnosis. With one exception, no patients tested were found to have normal intelligence

Study Name	Sample Description & Size	Findings
(Klinge & Dorsey, 1993)	Patients admitted to Atascadero State Hospital from 4/1/91 to 12/31/91. 650 patients were admitted during this time period. 22 went to a special voluntary unit, the remaining 628 admitted through the regular Admissions Unit. Nearly all patients were referred by the California court system, nearly all were involuntarily admitted. Ethnic breakdown of the sample Caucasians =190, Afro-Americans = 104, Hispanics =38, Asians = 9, Other = 9 (American Samoan, Native American, and several of mixed racial heritage). 70%-75% of patients are diagnosed as schizophrenic (the majority of whom are paranoid), 25-30% are diagnosed with affective disorders (primarily bipolar) and/or organic 350 were testable (56%) on the Woodcock-Johnson (Woodcock, 1977) and Kaufman Brief Intelligence Test (Kaufman & Kaufman, 1990)	• mean grade level complete = 11.25 • Range of grade-level completed included 2 patients who only completed second grade, and one patient who had 24 years of schooling and a Ph.D. plus post-doctoral training in engineering • On the Kaufman test, mean standard score total IQ = 88.3 (SD = 11.1). The mean Vocabulary IQ was 89.2 (SD =10.4) and the mean Matrix IQ = 85.% (SD =14.3) • Mean score was 7.5 grade on Woodcock-Johnson about 4 years below the mean school grade completed (11.2).151 individuals (43%) fell at or below a sixth-grade reading level. 158 (45%) had a reading level at or above the eighth-grade level

Table 2: Health Literacy Studies of People in State Hospitals

The findings from these three studies (Berg & Hammitt, 1980; Coles et al., 1978; Klinge & Dorsey, 1993) are similar. Many people living in state institutions are challenged with low literacy. Klinge and Dorsey noted that many common psychological tests such as the Minnesota Multiphasic Psychological Inventory (MMPI) require reading at an eighth-grade level or higher. They also concluded that "assessment tools available to the psychologist in the forensic psychiatric facility are less than adequate to evaluate the needs and abilities of today's patient" (p. 597). Berg and Hammitt concluded that "the literacy demands placed on psychiatric inpatients probably far exceed their literacy skills" (p. 267). From these three studies, one may wonder if health literacy is, in substantial part, a function of marginalization, time and intensity along with associated helplessness and impeded self-determination?

From a research design perspective Berg and Hammit (1980), Coles and colleagues (1978) and Klinge and Dorsey (1993) all used cross-sectional designs. Berg and Hammit (1980) used consecutively newly admitted patients as their participants (n = 100). The Coles et al., (1978) study used hospital patients who had been institutionalized for a cumulative period of 2 or more years and had most recently been hospitalized for a minimum of six months (n = 48). Klinge and Dorsey(1993) used patients referred to the state hospital by the court system (n=350). Notably, there are no additional health literacy studies of state hospital populations since Klinge's and Dorsey's study was published nearly 30 years ago.

People Who Are Homeless

The results of the literature search found two articles that addressed health literacy with people experiencing homelessness (See Table 3 for more detailed information on the findings). Christensen and Grace (1999) studied low health literacy amongst people who sought mental health services at a shelter-based clinic. The researchers concluded that the participants' comprehension skills were likely much lower than shown by their data. The researchers urged mental health care providers to become aware of the prevalence and management of limited literacy in their respective practice settings. They further encouraged practitioners to be mindful that most patients will not understand the majority of educational hand-outs and consent forms because such materials are often written at a tenth-grade level or higher *(Davis et al., 1994; Weiss & Coyne, 1997)*. Sleath and colleagues (2006) assessed literacy and perceived barriers to medication-taking among mothers and children who were homeless. As compared to Christensen and Grace (1999), the Sleath study is a more complex study of health literacy because it also is addressing caregiving with mothers who are experiencing homelessness. However, because the REALM only measures vocabulary recognition both studies may have underestimated health literacy levels because they also did not assess reading comprehension or other health literacy skills.

Table 3

Health Literacy of People Who are Homeless

Study Name	Sample Description & Size	Findings
(Christensen & Grace, 1999)	45 patients seeking services at a shelter-based clinic (approximately half were homeless), age range 19-67, mean age = 32 16% had diagnoses of schizophrenia, 60% had affective disorder diagnoses, 4% had diagnoses of adjustment disorder	• 34 participants or 76% read at or below the 7th grade level on the REALM. 10 participants reported they read "very well", 16 participants read "well" and 8 participants reported that they read "not well".

Study Name	Sample Description & Size	Findings
(Sleath et al., 2006)	164 mothers with one or more dependent children from 18 homeless shelters in North Carolina; 136 or 83% identified as black; 26 or 16% as nonblack; 56 or 33% had less than a high school education; 31 or 20% had a school diploma; 63 or 38% had more than a high school education	• 38 mothers (23%) scored below high school reading level; 119 mothers (73%) read at the high school level using the REALM. • Women who scored below high school reading level reported more barriers to giving their children prescribed medication • Medical literacy was not statistically significant as to whether mothers felt there were barriers to their children taking medication • Women who scored below high school reading level were more likely to report a barrier giving their children prescribed medication than women who read above a high school level • Younger women were more likely to report a barrier to giving their children a prescribed medication than older women • Preferred to receive both written and oral drug information

Table 3: Health Literacy of People Who are Homeless

Researchers (Christensen & Grace, 1999) and (Sleath et al., 2006) used the same instrument (REALM) to measure health literacy. Christensen and Grace conducted a basic exploratory study; while Sleath's team of researchers explored a different aspect of health literacy with women diagnosed with psychiatric and substance use disorders who were also mothers. Christensen and Grace did not ascertain their participants' parental status. The REALM does not measure comprehension. The REALM most likely overestimates health literacy levels since it only assesses word recognition. Both of these studies suggest that many people who are homeless may also have low health literacy. There are several studies that explore literacy issues amongst caregivers and the children they care for. However, only the Sleath article addressed caregivers with mental health challenges.

Health Literacy and People with Depression

The results of the literature search included two articles addressing health literacy and people experiencing depression (see Table 4 for more detailed information on the findings). When updating the literature review, the researcher thought there would be newer studies on health literacy and people experiencing depression. This was not the case, however, there were several studies that mentioned depression as a variable with other health conditions not as the main topic of interest, for example, Demian and colleagues' (2016) study on health literacy and medication adherence in adult kidney transplant patients.

Table 4

Health Literacy of People Experiencing Depression

Study Name	Sample Description & Size	Findings
(S. A. Smith & Moore, 2012)	Hypothesized that depression impairs health literacy and impedes efforts to promote health literacy through home visitation Quasi-experimental nationwide study using six sites Analyzed 2752 parent child dyads from AHRQ/NIH database	• Parents made significant improvements in health literacy ($p < .001$) • Parents with depression demonstrated lower baseline health literacy than parents without depression; parents with depression achieved greater gains in health literacy than non-depressed parents ($p < .001$) • After 1-yr of enhanced home visitation, vulnerable parents were better able to manage personal and family health and health care especially if they experienced depression

Study Name	Sample Description & Size	Findings
(Zaslow et al., 2001)	351 African-American families in which the mother had applied for or was receiving welfare. 52.6% of mothers had low literacy scores near the beginning of the study. 39.5% reported high levels of depressive symptoms 24.6% had co-occurring high levels of depressive symptoms and low literacy	• Neither depressive symptoms or low literacy nor the interaction of these two variables were predictive of employment Statistically significant interaction of literacy level and extent of depressive symptoms with less favorable child development outcomes

Table 4: Health Literacy of People Experiencing Depression

Cohort families participated in home visitation programs designed to augment parents' reflective skills. Visitors monitored depression, health- and health care-related practices, and surrounding family conditions at baseline and 6-month intervals for up to 36 months using the Life Skills Progression instrument. Smith and Moore examined differences in initial depression ratings for demographic subgroups and explored patterns of change in health literacy among depressed versus not-depressed parents. Correlation analysis showed that at each of four assessments better depression scores were consistently and positively correlated with use of information and services ($r = 21–22$, $p < .001$) and with self-management of personal and child health ($r = 42–49$, $p < .001$). Overall, parents made significant improvements in health literacy ($p < .001$). As hypothesized, depressed parents demonstrated lower baseline health literacy scores than not-depressed parents; however, they achieved greater gains ($p <.001$). While depression is linked with lower parental health literacy, after 1 year of enhanced home visitation, vulnerable parents were better able to manage personal and family health and health care, especially if depressed.

Enhanced home visitation may be an effective channel to enhance health literacy skills. Substance misuse is a common co- occurring condition that many people with psychiatric disabilities experience. Hence, I included addictions in this literature review because approximately 1 in 5 people have a co-occurring mental health and substance misuse diagnosis in any given year (Substance Abuse and Mental Health Administration (SAMHSA), 2012). Also, people with dual diagnoses or co-occurring disorders report that they use substances as a form of self-medication to control and manage emotional distress (Personal communication, anonymous, January 14, 2014).

Lincoln and colleagues (2006) hypothesized that low literacy would be associated with higher addiction severity, higher levels of depressive symptoms and worse mental health functioning compared to those with higher literacy in adults with drug and alcohol dependence. Lincoln and her colleagues' analysis were conducted on a prospective cohort analysis in the Health Evaluation and Linkage to Primary care (HELP) study. Researchers used the REALM (n=453). Three participants refused to complete the REALM instrument. Of these participants, 380 participants completed one follow-up interview. Longitudinal analyses were based on the subset of 380 participants. Baseline analyses identified 174 participants with low literacy; 52 (30%) read below a 6th grade reading level while 122 (70%) had a 7th-8th grade reading level. In adjusted analyses of baseline data, no associations were detected between health literacy and Addiction Severity Index Scale-Drug, the Addiction Severity Index Scale-Alcohol, the mental component summary of the SF-36 or the Centers for Epidemiologic Studies-Depression.

In longitudinal regression analysis, low health literacy was associated with higher levels of depressive symptoms which was consistent with the study's hypothesis.

Recent Health Literacy Studies of People Diagnosed with Serious Mental Illness Using Community-Based Services

Researchers (Currier et al., 2001) conducted a small descriptive study that assessed the reading skills of clients of a walk-in psychiatric emergency service. They also analyzed the reading level of some reading material that one might encounter in an emergency psychiatric service: a patients' rights handbook, a study consent form, a gun control form and a hospital general consent form. The reading materials sampled required reading skills of at least a high school level. Approximately half of the subjects in their study did not demonstrate literacy skills that were adequate to read the sample reading materials (see Table 5).

Table 5

Recent Health Literacy Studies of People Diagnosed with Serious Mental Illness Using Community-Based Services

Study Name	Sample Description & Size	Relevant Findings
(Clausen et al., 2016)	Sample from a mid-West psychiatric rehabilitation program 71 volunteers from a program with 631 clients. Compared three different measurement tools (REALM-SF, SILS, and NVS)	• Depending on the instrument used, study participants the prevalence of inadequate health literacy to be much higher. • According to the SILS which measured confidence completing medical forms, ≈ 40% of study participants needed some help

Study Name	Sample Description & Size	Relevant Findings
		• The result from the REALM-SF indicated ≈ 50% were found to have inadequate health literacy • The NVS that also measured numeracy skills indicated that 70% of study participants were found to have inadequate health literacy skills.
(Currier et al., 2001)	Random sample of 55 person visiting a psychiatric emergency service. 50 of 55 agreed to participate. Nearly two-thirds of participants (64.2%) were male, 38.8% of participants were female. Almost half (48.1%) of participants were African American, 38.5% were Caucasian, 13.4% identified as other. Diagnoses included schizophrenia (53.8%), mood disorders (38.5%), and other disorders (7.7%). More than half (56.6%) had history of drug or alcohol abuse. A little more than one third of participants (36%) had less than a 9th grade education. Used Wide Range Achievement Test (WRAT, (Reid, 1996) to measure literacy.	• Hospital documents used: study consent form, gun control form, patient rights handbook and hospital general consent form. Nearly all material required a high school level of literacy—half of participants were unable to read these documents.
(Degan et al., 2019)	Australian study to determine if participants attending mental health treatment had health literacy levels that differed from other populations.	• Participants had specific difficulties in appraising health information, navigating the healthcare system, and finding good health information. Compared with other populations, this sampled tended to have lower health literacy scores. There is a

Study Name	Sample Description & Size	Relevant Findings
	Sample size (N = 325). Used HLQ.	higher rate of low health literacy amongst people diagnosed with mental illness.
(Degan et al., 2021)	14 studies were included in this systematic review.	• Researchers found that there is a lack of research between health literacy and other outcomes especially health service engagement. •
(Galletty et al., 2013)	30 people with schizophrenia and 30 people with major depression. Assessed health literacy with TOFHLA in Australia	• Health literacy level in participants comparable to Australian general population and considerably higher than the level reported in US studies • No association between health literacy level and medication compliance • Results suggest that poor health literacy does not explain medication nonadherence
(Krishan et al., 2012)	256 individuals diagnosed with serious mental illness. Part of a larger randomized study evaluating the effects of a medical care management intervention. Hypothesized that low health literacy would be associated with lack of health insurance, worse health status, the presence of a psychiatric diagnosis, more inpatient hospitalization, and emergency department visits and lower use of preventive services. Used REALM to measure health literacy. Mean age of sample was 46.05 ± (SD 8.13 years. 207 participants	• Mean REALM score = 55.18 (SD±15.6) equals approximately a 7th or 8th grade reading level • 117 (46%) participants had low health literacy. When analysis was controlled for education, race, gender, age and schizophrenia diagnosis, low health literacy was associated with increased odds of inpatient medical hospitalization (OR = 3.17, 59% CI = 1.49-9.22, *p* = .005)

Study Name	Sample Description & Size	Relevant Findings
	(81%) were African American. Slightly more than half were males (n=132). 2/3 (n=168) reported at least a 12th grade education. 106 (41%) were insured. Study was reported in letter to editor—not peer-reviewed.	
(A. K. Lincoln et al., 2008)	Pilot study (12 interviews) findings led researchers to change recruitment strategy by changing how they described the study due to potential stigma associated with low health literacy. Convenience sample of 100 patients. Participants had a range of diagnoses with 31% reporting two diagnoses and 21% reporting 3 or more diagnoses	• REALM score = 55.88 (SD ±13.89) which is about a 7th to 8th grade reading level
(Rose et al., 2014)	Purposive sample of individuals with diagnosis of serious mental illness at three different community mental health centers (n=98), Site A: n=52, Site B: n= 26, Site C: n=20.	• 51% of sample scored at 8th reading level or below on REALM-SF. • 37% of participants had marginal or inadequate levels of health literacy on STOFHLA • Chi-square analyses found a statistically significant association between health literacy and medication adherence (*p* =0.02) • Statistically significant relationship between TOFHLA Raw Numeracy score and Morisky Adherence Scale (Morisky et al., 1986). TOFHLA

Study Name	Sample Description & Size	Relevant Findings
		scores decreased .55 for every 1 point increase in Morisky scores. • 40% of sample had inadequate or marginal health literacy scores. • More than 60% scored in the adequate range of health literacy • People with lower health literacy scores had higher scores on the Hill-Bone Adherence scale for Sodium Intake Subscale (Kim et al., 2000). • No statistically significant relationship was found between TOFHLA raw numeracy scores and "current smoking" alone or when controlling for education, study location or both. • No statistically significant relationship between health literacy and "most drinks consumed," "minutes of vigorous exercise during the past week," or BMI

Note: Bolded article references are new since original literature review was written.

Table 5: Recent Health Literacy Studies of People Diagnosed with Serious Mental Illness Using Community-Based Services

Lincoln and colleagues (2008) conducted a study at an urban behavioral outpatient safety net clinic. Lincoln (see Table 5) discussed that when they initially piloted the study, potential participants were told that they were studying the relationship between mental health and literacy. Disproportionate numbers of participants had high literacy scores which caused Lincoln and her team to consider that the stigma of literacy may be influencing the participation in their study. The researchers, therefore, revised their recruitment strategy to ask if participants were interested in participating in a study on education and health. In a convenience sample of 100 patients, 61 were male. The mean REALM score was 55.88 ± (SD =13.89) and indicates a seventh-to-eighth grade reading level.

Lincoln's and colleagues' (2008) study is one of the more recent studies that includes people with a range of psychiatric diagnoses. Thirty-one percent of the participants had two diagnoses and 21% had 3 or more diagnoses. According to Lincoln limited literacy was associated with psychotic disorders and lower levels of formal education and higher literacy was associated with post-traumatic stress disorder and substance abuse disorder. After controlling for race/ethnicity, age and intelligence scores, participants with psychotic disorders were more likely to have lower literacy scores (OR =2.4, p<0.14) than participants without psychotic disorders. Participants without substance abuse and post-traumatic stress disorder were less likely to have limited literacy than people with these disorders (OR =.29, p <0.2 and 0.39, p < 0.14, respectively).

Researchers (Krishan et al., 2012) reported in a letter to the editor of *Psychiatric Services* about a study of individuals diagnosed with severe mental illness and receiving services at a community mental health center (CMHC) (n=256) (see Table 5). They stated that the parent study was a randomized trial assessing the effects of a medical care management intervention for individuals being treated at the CMHC. Krishan's team hypothesized that low health literacy would be associated with lack of health insurance, worse health status and the presence of a psychiatric diagnosis, more inpatient hospitalizations and emergency department visits and lower use of preventive services.

Krishan used the REALM to measure health literacy. 207 of the participants identified as African American. Fifty-two per cent of the participants were male. Two-thirds participants (n=168) reported at least a 12th grade education. A little less than half (n=117) had low health literacy. The mean REALM score was 55.18±15.60. Low health literacy was associated with increased odds of inpatient medical hospitalization when the research team controlled for age, education, race, gender, age and schizophrenia diagnosis (OR= 3.71, 95% CI = 1.49-9.22, p<.005). It should be noted that of the three odds ratios reported in this study, two did not meet statistical significance, and the other odds ratio is so small that it is not meaningful. It is somewhat confusing as to why the authors chose to report this information without additional explanation.

Rose and colleagues (2014) studied cardiovascular health literacy and treatment adherence in persons diagnosed with serious mental illness (n=98), the only study the researcher found focused on physical health with this population focus. Rose and her colleagues hypothesized that people diagnosed with serious mental illness and had low health literacy could have difficulty with adherence to treatment recommendations (e.g., medication regimens and follow-up appointments). Risk of cardiovascular disease in people diagnosed with serious mental illness is greater than in the general population (Osborn et al., 2008).

Rose and colleagues (2014) used a survey to assess the health literacy, health status and health behaviors of their participants (n=98). The participants were currently receiving care in urban community psychiatric centers in three locations. The researchers used a descriptive correlational study design to explore the relationships among health literacy, cardiovascular medication adherence and cardiovascular health in a sample of people diagnosed with serious mental illness and documented cardiovascular health risk factor(s). Rose and colleagues used the ((HHS), 2000) definition of health literacy and both the REALM-SF (Bass III et al., 2003) and the STOFHLA (Parker et al., 1995) to measure health literacy.

Rose and colleagues (2014) commented about their surprise at the finding that people with lower health literacy had higher adherence to the sodium restriction intake. In their commentary, Rose's team dismissed this finding and did not give it any credence because of studies (Claro et al., 2012; Dickson et al., 2011) that found research participants underreported their salt intake. While I do not entirely disagree with Rose's team's findings, traditional researchers have dismissed the perceptions of people diagnosed with serious mental illness in favor of expert views.

Upon reflection, Rose's findings are reasonable. People diagnosed with serious mental illness have had their perceptions discredited for so long. Therefore, I find myself in a place of cognitive dissonance with this finding and with some of the scholarship that reflects more quantitatively oriented, positivist research studies. Deegan (2000) quotes one psychiatric survivor, Esso Leete,

> "I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can voice my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies," (p. 203).

Discussion

Based on my practice experience, I developed a patient education curriculum at the request of a group of patients on how to talk with a psychiatrist about medication concerns. The curriculum was well-received and is still in use today nearly 15 years later.

People living with mental health diagnoses are hungry for information to increase their health literacy. My practice experiences are not reflected in the health literacy literature. Health literacy is viewed as a skill deficit that is primarily due to the inadequacy of the individual. There is little discussion on how to make an incredibly complex system more user-friendly and adapt information to meet the needs and desires of patients. There is even less curiosity about how people with low literacy manage to navigate the health care system and the strengths and competencies they develop to cope with a system that may not meet their needs.

Observations and Gaps in the Health Literacy Literature

Few, if any, studies of health literacy and people diagnosed with mental health conditions are of those who live in rural and frontier settings. Most health literacy studies focused on people diagnosed with mental illness located in urban areas. People living with mental health conditions in rural and frontier settings often face discrimination and stigma from the community (Stewart et al., 2015). They worry about having their car parked at the mental health clinic (if there is an accessible local clinic) because it might be recognized and their neighbors will talk. The association of fear and discrimination because of one's health condition and how it may be related to low health literacy has not been investigated.

With the exception of the oldest studies (Berg & Hammitt, 1980; Coles et al., 1978; Klinge & Dorsey, 1993), few studies involved the range of diagnoses that one would encounter at a publicly funded mental health clinic. Only three studies (Currier et al., 2001; Krishan et al., 2012a; A. K. Lincoln et al., 2008) involved people with a range of diagnoses. People who experience voices, visions, fear and mood swings have a greater need to increase their health literacy, given that their experience of reality may change more often than it does for people who do not experience such things. When people experience voices, visions, fear, and mood swings, those “symptoms” or experiences are often accompanied by cognitive challenges that may impact a person’s health literacy.

Three studies (Currier et al., 2001; Krishan et al., 2012a; A. K. Lincoln et al., 2008) included a similar population that I deem to be of critical importance: urban, community-living people diagnosed with severe mental illness using publicly funded mental health services. Yet, none of these health literacy studies was service-user-led or -directed. They focused on the health literacy question using a medical lens. Furthermore, none of the studies asked participants with low health literacy how they managed or what they did when they needed to make health care decisions.

Another large population excluded from most health literacy research are justice-involved persons residing in jails, state and federal prisons. According to (James & Glaze, 2006), 60% of jail inmates had symptoms of a mental health disorder, 49% of state prisoners had symptoms of a mental health disorder and 40% of federal prisoners had symptoms of mental disorders. Little is known about the health literacy needs of this population.

Not surprisingly to those of us diagnosed with severe mental illness, people with diagnoses of serious mental illness are often excluded from participation in research for health conditions and health issues (e.g., health literacy, heart disease, diabetes) unless we are the population of focus. This is despite frequent documentation that we experience worse health outcomes than our same-aged peers without diagnosis of mental illness (Bogart et al., 2006; Desai et al., 2002; Felker et al., 1996; Jones, Howard, & Thornicroft, 2008; Karasu et al., 1980; Koranyi, 1979; Levinson Miller et al., 2003; National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, 2006; Newman & Bland, 1991; Sullivan, Han, Moore, & Kotrla, 2006; Thornicroft et al., 2007. The one exception to this exclusion in the scholarship on health literacy is people diagnosed with depressive disorders. Researchers may exclude people with mental illness from research due to their stereotypes and misconceptions about our vulnerability and our capacity to consent and the need to have appropriate supports to minimize risk to participants (Yanos et al., 2009).

Definitions

As discussed in the Chapter one, few health literacy definitions were developed in consultation with people with inadequate health literacy or more specifically people diagnosed with serious mental illness who use publicly funded health care. Rather, most definitions were developed by researchers and professionals from the fields of adult basic education, literacy, medicine, and other related professionals. Jordan and colleagues' (2010) study on health literacy definitions was one of the few that involved speaking to service users about their conceptual understanding of health literacy. Their study participants included a few people who self-identified as individuals who used mental health services.

Few definitions identified by (Sørensen, et al., 2012) (see Appendix A) address the role of culture in health literacy. Culture is most notable in the communication aspect of health literacy. Culture impacts belief systems, communication styles, and understanding and responding to health information (Glassman & Almader-Douglas, 2013; Hill, 2004). The absence of culture as a component of the definitions of health literacy may be viewed as a manifestation of dominant Western-European cultures and structural oppression and may contribute to health disparities.

Health literacy definitions are further challenged because the skills required to be health literate are not used continuously in any one episode of health care service. Even in a specific episode of health care service, (e.g., a primary care provider visit), a person may need the skills of completing health insurance paperwork, which usually happens at the beginning of the episode of care. The patient then must transition to the use of skills required to communicate with their doctor about their health concerns. The health care system determines the skills that are needed and when they are to be used.

Another reason health literacy is difficult to define, operationalize and measure is that not all tasks are equal in terms of their demands and complexity among people and populations. Some tasks may be viewed as simple (and may be for some people), such as identifying one's racial/ethnic identity on a form. The question becomes more complex if the way one identifies is not listed on the form (e.g., people who have multiple racial/ethnic identities). Tasks also become more complex if they privilege the experiences of the dominant cultural groups over those who do not identify as members of dominant cultural groups. Because health literacy definitions “do not address receptive and oral communication skills that are necessary to navigate the health care system,” (Greenberg, 2001), the lack of information and skills may lead to people not knowing what is important to share with a health care provider In addition, patients may not understand what they are being told, particularly in challenging situations where people disagree with or feel ambivalent about what they are being told. The health care system and the medical model put the onus of responsibility on the individual. With few exceptions, by and large, the health care system continues to develop its complexity separate from the needs of patients and service users.

While much improved, there are still some limitations with (Sørensen, et al., 2012) integrated model of health literacy. Health literacy still appears to be a static concept in the model. Curiously, communication tasks (such as providing information and asking questions) are not specifically addressed in this framework. Also, several health conditions could impact one’s health literacy level at various times. For example, a stroke injury could impact a person’s health literacy and a person’s ability to communicate and/or understand information. Other conditions that could impact a person’s health literacy include severe emotional distress, whether due to interpersonal violence, active symptomatology of mental illnesses, cognitive impairments such as dementia, Alzheimer’s, Huntington’s disease, and so on. Also, social stressors such as poverty, interpersonal violence, and other social problems can lower one’s health literacy skills when dealing with other socio-economic stressors.

Early definitions of health literacy did not include communication as a health literacy skill. Communication includes not only receiving information, but also providing relevant information.

Table 6

Summary of Issues and Concerns about Health Literacy Definitions and Measurement

Definition	Measurement
• Definitions developed by professionals with little input from people at risk or lived experience of inadequate health literacy • Definitions do not reflect dynamic nature of health literacy given people's experience of extreme states, distress and other stressors • Very few people diagnosed with labels of mental illness have been consulted in the definitions of health literacy	• Measures assume health literacy is static, not dynamic • Most measures address vocabulary recognition and reading comprehension aspects health literacy. Some measures also address numeracy. Most measures fail to address communication aspects of literacy • Most measures address deficits and do not identify strengths or what people do to make medical decisions even when they have inadequate health literacy

Table 6: Summary of Issues and Concerns about Health Literacy Definitions and Measurement

Implications for Empirical Research

People diagnosed with serious mental illness and who use publicly funded health care are at high risk for low health literacy. While there is a vast amount of health literacy research, little of the research focuses on this population and much of it is not current. The research literature fails to acknowledge or address the complexity of today's health care system. Finally, very few studies actually talk with patients about how low health literacy impacts them or asks them about solutions to remedy the challenges they encounter. Some recent literature explores depression and health literacy in different populations of people diagnosed with serious mental illness (e.g., young mothers, older adults). However, there is great diversity among people who share the same diagnostic labels—not just diversity in the social groups to which we belong but also in our experiences of these labels.

While studies have focused specific attention on the conceptualization and operationalization of health literacy, it should be noted that literature on health literacy can be understood to reflect a broader body of literature on healthcare quality. While the focus of this thesis is on health literacy, both literatures have sought to identify essential practices and processes.

For example, Ljungberg and colleagues (2015) identified the several factors that were deemed essential to positive relationships with mental health professionals. These included time and availability on the part of providers; providers should be prepared to offer social support; and providers should be someone that is easy to be with and talk to. The scholars also suggested that mental health professionals should work together for the needs of the individual including sharing decision-making within the relationship; involving relationships that went beyond the roles of service user and professional that were mutual and reciprocal. At a basic level, Ljungberg and colleagues (2015) asserted that a shared humanness that involves kindness, having patience, and being involved is essential for positive relationships between service users and mental health care providers. Similarly, other researchers (Hannawa et al., 2021) identified consistent, well-organized care as an example of a structural feature of healthcare quality. In the same study, patients considered intrapersonal and interpersonal care processes as equally important in good quality care.

Similar recommendations have been provided in an effort to make sustained improvements in mental health and healthcare systems, particularly from the perspectives of service users. For example, Ayalon and Alvidrez (2007) talked with Black recipients of mental health services to identify barriers and facilitators that hampers access to and the continued use of mental health services. These barriers and facilitators can also be viewed as characteristics of healthcare quality and health literacy. Some of the participants' self-identified barriers included questions about psychotropic medications such as wondering if they were 'going to be on meds forever?'; and if so, what 'long term effects' they would have on them? (p. 1328).

Ayalon and Alvidrez's (2007) study participants identified systemic barriers that made it difficult to even get in the door of the mental health center. Their participants discussed that getting appropriate information about and appropriate referrals for mental health treatment was crucial. Participants described receiving irresponsible, inadequate, and incompetent treatment. Participants also described not being told why they were taking medication or the importance of taking the medication. Ayalon and Alvidrez's participants also described the importance of being treated as a human being.

In summarizing the literature, the following reflections inform the approach and methodology of my research study on health literacy among people diagnosed with mental illness:

- The literature suggests that people diagnosed with mental illness are at increased risk for inadequate health literacy;
- More studies have been conducted with people who experience depression rather than the range of people and their diagnostic diversity that one encounters in publicly funded mental health services;
- Health literacy studies with people diagnosed with mental illness do not attempt to address the challenges that people have when they experience extreme duress; and
- While a broader literature does focus upon the question of how to improve healthcare quality from the perspective of users of publicly funded health and mental health services, there are very few studies where researchers actually talk to these people about health literacy and what would help them improve their health literacy.

Chapter Three: Approach and Theoretical Framework

In this section, I locate my social position and discuss the theoretical framework and approach to my research on health literacy. After discussing my social location, I discuss survivor/user approaches to research and the social model of disability. Finally, I discuss the principles and values that guide this research.

I approach this research from the following standpoint: I identify as a white cis-gendered psychiatric survivor, and I still use mental health services. I am a lived-experience researcher. As a psychiatric survivor, I have been homeless three times for varying lengths of time, with the longest being 1.5 years. I have been hospitalized more than 20 times, some against my will, and secluded and restrained. I used psychotropic medication for several years and experienced psychotropic polypharmacy[2] for several years.

Most medical and mental health practitioners that treated me were guided by a system of medical research and practice and operated from a particular framework. Few practitioners included the perspective of people most impacted by their conclusions. While some of those treatments were beneficial, many of those treatments were ineffective, limiting, administered in an authoritarian manner, objectifying, oppressive, stigmatizing and restraining to aspects of my full potential as a human being.

These experiences inform my social work education, practice, research and training. As a scholar-researcher and advocate-practitioner, I am conscious that being

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[2] Psychotropic polypharmacy is the use of two or more medications to treat the same mental health problem, or taking two or more psychiatric medications in the same medication class (such as antidepressants or anti-psychotic medications).

white, cis-gender, and able to navigate in the worlds of consumers/survivors/ex-patients (C/S/X) and providers gives me more privilege than many of my peers.

I therefore wrestle with my insider-outsider relationship as a researcher. There is significant emotional labor and complex ethical and political dilemmas involved in using my lived experience and the lived experiences of others and service use in the full range of healthcare use as an 'instrument of knowing' and understanding in mental health research.

Common approaches to producing knowledge include lived experience, searching the internet, talking to people who have a certain experience, reading books, using a map and research. One key difference between research and other forms of knowledge production is that research relies on systematic and formalized methods of discovering something previously unknown (Beresford & Rose, 2009; Sprague & Hayes, 2000). Because research uses systematic and formalized methods of discovering new knowledge, it has become more highly valued and privileged than most other ways of producing knowledge and is highly objectified.

The valuing and privileging of objective research over other forms of knowledge production can coincide with and reinforce the devaluing of experiential knowledge from people on the margins of society, such as those who have been diagnosed with serious mental illness (Beresford, 2003b; Fleishmann, 2009; Wallcraft & Nettle, 2009a). People diagnosed with serious mental illness often experience discrimination, stigmatization and marginalization in society. As such, the knowledge and experiences of people diagnosed with serious mental illness are neither highly valued nor treated with respect. Although research is privileged and granted authority, it is subject to broad political processes that influence the nature, focus and effect of research (Beresford & Rose, 2009). Thus, research should be subject to the same close scrutiny as less formal types of knowledge.

Roberts (2000) discusses the tension and, at times, competition between narrative and evidence-based practices in the mental health world. Some of this tension and competition is born because the treatments of human ills and other mental illnesses are leave a lot to be desired. The medical treatments that do work do not work for everyone (Szatmari, 1999). Also, said treatments are not without health effects that can make physical problems worse (e.g., weight gain, heart problems, tardive dyskinesia, to name a few), and may be life-threatening at times, too. Also, many of the medications can dull emotions, affect libido, and cause many other problems.

The C/S/X community adopted a slogan in response to the evidence-based practice movement that claims, “We are the evidence!” By not including the stories of people with lived experience, then as Roberts (2000) claims evidence-based practice “risks losing the meaning and significance of the very things it so carefully measures in such a reproducible way,” (p. 439).

Traditionally, social work and medical theories of mental health problems have not systematically involved people who use their services in theory development (Beresford, 2000b). However, the Code of Ethics (National Association of Social Workers, 2008) requires social workers to seek social justice for our clients using research as a tool. What better way to honor our Code of Ethics than creating new knowledge with people who have lived experience of mental illness!

Disability Rights Movement

The Disability Rights Movement (DRM) as well as service users and survivors (of the mental health system) have produced our own knowledge based upon lived experience, generating our own conceptual frameworks and theories. While there is much similarity between the disability rights movement and the users/survivors' movement, there are also some distinct differences (Rapley, 2001) that I will explain further in the following paragraphs.

The DRM has been and continues to be a social movement that strives to solve a social problem through understanding the problem and its sources. It evolved in order to contest and rebel against the marginalization of persons with disabilities. The movement developed in three phases, In Phase 1, persons with disabilities developed a definition of what the problem was (is), and what its sources are. In the second phase participants in the movement developed a consensus and developed a collective solution to the problem. The third phase responded to the consequences of new policies and disabilities (Winter, 2003).

Defining the Problem

Oliver (1990) a prominent disability studies scholar, described the social problem as the marginalization and oppression of people with disabilities. Similar to racism, sexism and other forms of oppression, the sources of the problems operate at the personal, interpersonal, and structural or institutional level (Winter, 2003). Looking through the lens of the DRM, the marginalization of persons with disabilities; lies in the prejudices, misconceptions and good intentions of people without disabilities and occurs when non-disabled people and persons with disabilities interact. Also, Winter argued that the marginalized oppression of persons with disabilities is reinforced and built through the dominant ideas and hegemonic practices of a "plausibility structure" (Berger & Luckmann, 1966). This structure allows society to exert control of the factors that influence and make plausible the definition of the situation of people with disabilities by otherwise reasonable people (Winter, 2003). However, the DRM views the plausibility structure as the primary source of the marginalization and oppression of people with disabilities. In other words, "the oppression of people with disabilities does not [always] derive from a backward set of attitudes" (p. 5). Rather, "it is the product of [the] dominant culture" (p. 6) that, while often well-meaning, nevertheless "marginalizes people" with disabilities (Charlton, 1998).

Winter (2003) contended that the first phase of the DRM defined the claim that people with disabilities are: "1) subject to marginalization; and 2) are, consequently, oppressed…And in order to understand the problems encountered by persons with disabilities, the disabilities rights movements makes important distinctions between: 1) impairment and disability, and 2) stigmatization and marginalization" (p.6). Winter's argument also applies to people diagnosed with mental illness. Depending on other vulnerabilities that people diagnosed with mental illness have (e.g., race, gender, sexual identity), their experiences of being diagnosed may be multi-layered and not just unidimensional.

"Impairment" is defined as the condition of a person "lacking part or all of a limb, organ, or mechanism of the body" (Union of the Physically Impaired Against Segregation

(UPIAS), 1976) as cited in (Barton, 1998). “Mechanisms of the body” include sight, hearing, executive function, reading, etc. Winter (2003). According to Winter "disability" is "the disadvantage or restriction of activity caused by a contemporary social organization which . . . excludes [people with physical impairments] from participation in the mainstream of social activities." In other words, people who have impairments "are disabled by a society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dexterous" (Brisenden, 1998).

“Disability” is "the disadvantage or restriction of activity caused by a contemporary social organization which . . . excludes [people with physical impairments] from participation in the mainstream of social activities" (UPIAS, 1976) as quoted in Barton (1998). Social organization in this context is a combination of the mainstream culture, the social structure, and the dominant ideas about what is right, what “normal” is, and how things ought to be done (Winter, 2003).

Examples of the differences between disability and impairment include the study (Groce, 1985) of two New England towns where many people were congenitally deaf. Although it could be said that the people who were congenitally deaf were impaired, they were not disabled because everyone in the town spoke sign language (Winter, 2003). Many people have poor eye-sight and require corrective lenses to see. While people who wear glasses or contact lenses or glasses have an impairment, they are not considered disabled by society because they generally are not excluded from participating in society as wearing glasses or contacts is not viewed as a mark of a disabled person (Barnes et al., 1999).

Stigmatization, according to (Goffman, 1965), is the process that occurs when a person comes to be viewed as having a mark or “an attribute that is deeply discrediting” (p. 4). Goffman continues, "The central feature of the stigmatized individual's life . . . is a question of . . . 'acceptance.' Those who have dealings with him[/her] fail to accord him[/her] the respect and regard which" would otherwise be their due” (p. 8). (Corrigan & Watson, 2002), break stigmatization down further. “Public stigma” is the reaction that the general public has to people with mental illness” (p. 16). “Self-stigma” “is the prejudice which people with mental illness turn against themselves,” (p. 16).

Stereotypes, prejudices and discrimination are separate components of public- and self-stigma. Stereotypes can be viewed as efficient social knowledge structures learned by most members of a social group. They are efficient because people can quickly generate impressions and expectations of people who belong to a stereotyped group. Prejudices are both cognitive and affective responses that lead to discrimination. When prejudice results in anger, hostile behavior is likely to ensue; and when prejudice results in fear, the ensuing behavior is avoidance that results in exclusion (Corrigan & Watson, 2002).

Marginalization is the process that keeps one on the outside or on the margins of activities, communities and groups in one’s social setting. The process denies people “citizenship…resources [and] access to education, employment, housing and other areas of life…life,” (G. Williams, 1998). Winter (2003) describes marginalization as the relationship one has with the economy and civic and governmental aspects of one’s community. (Michener & DeLamater, 1999) asserts that marginalization generally occurs in secondary groups where interactions “tend to be formal, impersonal and non-spontaneous” (p. 318) (e.g., in a bureaucracy). For instance, when one is marginalized, employers turn away qualified people simply because they have a disability and others struggle to gain access to resources to develop qualifications to be considered qualified.

Primary goals of the DRM include the elimination or amelioration of the marginalization of people with impairments, and their empowerment in order to influence social policies and practices to increase inclusion and full participation in society (Winter, 2003). Brisenden (1998) frames the goal as enabling persons with disabilities to say,

> …“we are able to take responsibility for our own lives…do not want or need [others] to manage our affairs; we best understand what is best for us; we…control our own organizations and programs and influence…government funding, public policy and economic enterprises that directly affect us. (p. 128).

The DRM prefers that people with disabilities not be marginalized or stigmatized given that its primary concerns are with the exercise of economic and political rights (Winter, 2003). Stigmatization, according to (Oliver, 1990) has focused on primary or interpersonal relations and fails to focus on political or economic rights. Hence, the DRM has chosen to focus on marginalization.

The Medical Model of Disability (Democracy Disability and Society Group, 2003) focuses on impairment in relation to the physical or biological cause of disability (see Figure 4) (Winter, 2003). The medical model places the locus of responsibility for the barriers on the individual and her/his impaired and dysfunctional body. The traditional medical model and the history of medicine McRuer (2006) assumes impairments and chronic illness are caused by physical, sensory or mental impairments.

The individual is impaired and is the problem. The focus of the medical profession is *to cure* the impairment and alleviate the affect. The medical model treats a person as one treats a person with measles or other illness. Treating people with disabilities/impairments as though they have illnesses requires people with disabilities to take on the sick role (Parsons, 1951).

The essential components of the sick role (Parsons, 1951) include privileges, exemptions, and obligations. The sick role privileges and exempts people with disabilities from "normal…responsibilities…relative to the nature and severity of the illness [or impairment]," and the exemption from moral accountability for the illness [impairment] (p. 437). In other words, when one occupies the sick role, there is no expectation to take care of oneself nor that one can do what needs to be done (Winter, 2003).

The exemption of people being unable to take care of one's self provides the bridge to the third component which is the obligation to accept help. The obligation of accepting help also requires that the impaired person (a) "wants to 'get well'" (p. 437) and being ill is considered undesirable; and (b) "seek technically competent help" (p. 437) usually that from a physician and cooperate with her or him in wanting and trying to get well. In other words, the sick role is viewed as a temporary role and creates dependency on the physician to ameliorate or cure.

Figure 4

The Medical Model of Disability

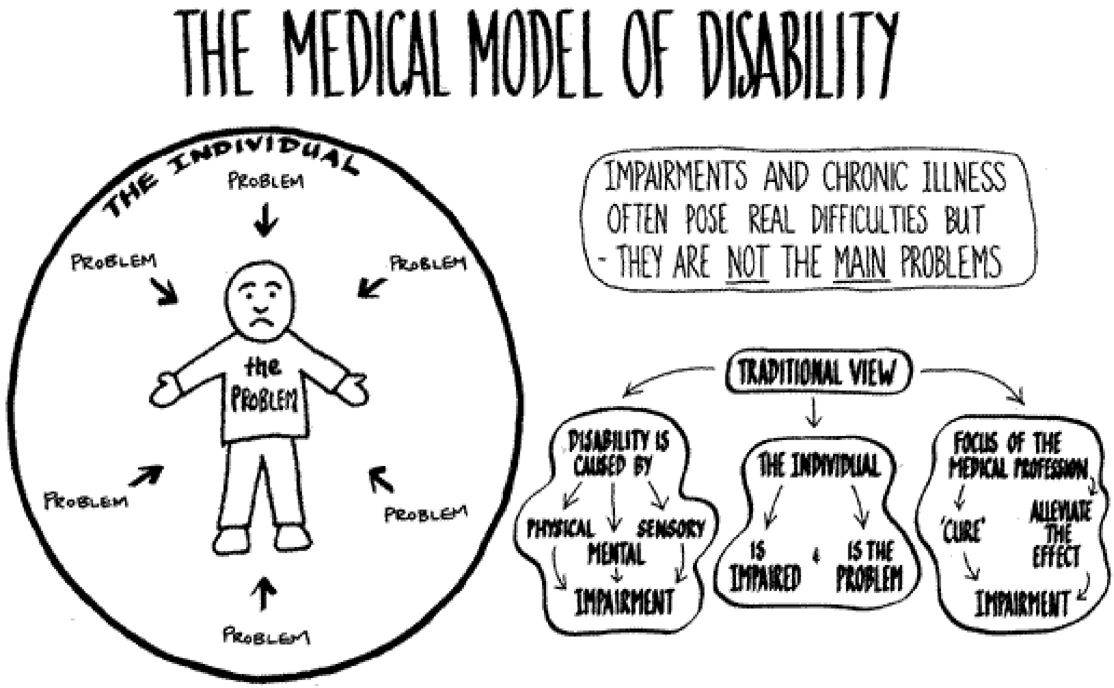

Figure 4: The Medical Model of Disability

Note: Taken from Democracy Disability and Society Group (2003a).

Crewe and Harkins (1983) argue that the medical model encourages people with disabilities or impairments to accept “the dependency under the sick role as normative for the duration” (p. 17) of the impairment. Winter's (2003) argument is in alignment with Crewe’s and Harkin’s. Winter claimed that the medical model constitutes a plausibility structure that—through its policies, procedures, and implicit premises (e.g., naming and defining the privileges and obligations of the sick role) serve to control and oppress people with impairments.

Kassenbaum and Baumann (1965) point out that where the impairment or "illness" is "not temporary…[the sick] role-expectations are clearly inapplicable (p. 18). Impairments may or may not be temporary. In fact, some impairments last a lifetime (Winter, 2003). Furthermore, when people with disabilities' problems are defined as "medical problems", then the solution presumes that our lives will be dominated by medical professionals (Barnes et al., 1999). The medical model represents a form of paternalism in its view of people with disabilities (Charlton, 1998) or more specifically, "people with disabilities…[are] unable to take responsibility for their own lives" (p. 53). In other words, the sick role in combination with the medical deprives people with disabilities of autonomy and the control of one's own affairs which is the defining mark of personhood (Winter, 2003).

The DRM's proposed solutions to the problem of marginalized oppression of people with disabilities has entailed a three pronged approach: 1) challenging the ideology of the medical model and proposing to replace it with a social model as the way to understand disability; 2) legislation, proposing new laws such as the Americans with Disabilities Act (ADA); and organizational, proposing the creation of Independent Living Centers so that people with disabilities can organize and be responsible for their own success (or failure) (Winter, 2003). There is much to be said about the second and third prongs. However, for the sake of brevity, I will focus only on the first prong—the Social Model of Disability (SMD—see Figure 5). As discussed previously, the old paternalistic medical model is a plausibility structure. It has a set of policies and procedures whose premises control the lives of people with disabilities (Winter, 2003). The medical model's structure oppresses people with disabilities as unable to act in their own best interest, deprives them of dignity and dehumanizes us. Fundamentally, social problems of people with disabilities are according to the medical model, simply, medical problems. Medical problems then require treatment by an array of medical providers. People with disabilities are expected to comply with medical treatment and take on the sick role, thereby increasing our dependency and limiting our ability to exercise our autonomy (Winter, 2003).

Figure 5

Social Model of Disability

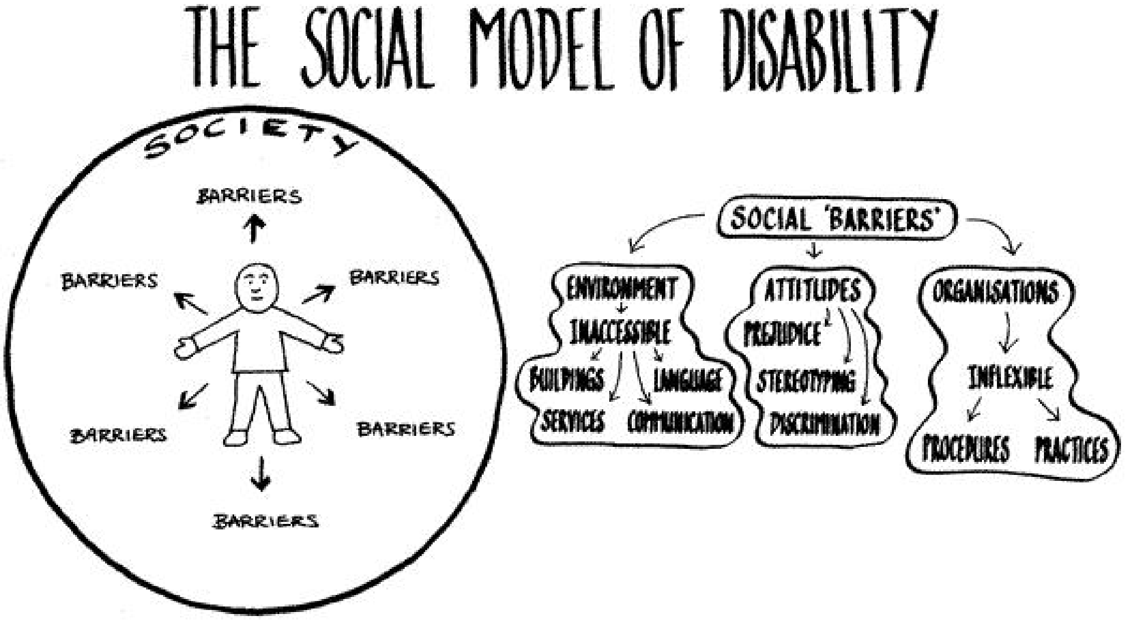

Figure 5: Social Model of Disability

Note: Taken from Democracy Disability and Society Group (2003b)

The SMD suggests that social conditions convert impairments into disabilities—not the impaired person. In contrast, the focus of efforts on behalf of people with disabilities should be rooted in respect for their personhood (i.e., on their ability to make their own autonomous decisions (Winter, 2003). That is, the focus of the social model is not “the welfare of the handicapped” but rather “the human rights of people with disabilities” (Charlton, 1998). In sum, disability is constructed both individually and collectively as a result of the views people without disabilities hold; and is manifested through social attitudes and in the stigmatization of people with disabilities (Winter, 2003). Brisenden (1998) clarifies by stating that people with impairments “are disabled by society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dexterous (p. 23), —and, I might add, have “normal emotions” and do not hear voices, see visions, have fears or experience great emotional distress.

Regardless of the specific restriction involved, the SMD views disability as a form of oppression. It is irrelevant to the SMD whether the oppression of people with disabilities is due to the collective lack of concern, uncaring or unknowing society or as individuals of circumstances (Oliver, 1990). The SMD does not deny the significance of impairment in people’s lives, but rather concentrates on social barriers that are constructed on top of the impairment. Banes and colleagues (1999) summarize this thesis by suggesting that “people with…impairments are disabled by society’s blatant failure to accommodate to their needs” (p. 2). This failure marginalizes people and prevents them from accessing activities in society that non-disabled people access every day.

The SMD’s second premise is that people with disabilities or impairments can and should take control of their own lives as much as possible. According to Winter (2003), everyone with or without impairments or disabilities have things they can and cannot do. One example I often use in training is to ask how many people call a plumber when they have a problem with their toilet. Most persons usually do not have the knowledge to solve plumbing problems. Brisenden (1998) argues that everyone has a range of physical and mental abilities "that are unique to the individual" (p. 23). The SMD makes it plausible to reject policy and practices founded in the idea that the impairment itself should define and inform one's conception of a person with an impairment or disability (Winter, 2003). When people with impairments or disabilities are described by their condition(s) or a noun, (e.g., the blind, the deaf, the mentally ill), their conditions are then equated with their personhood and they are deprived of other essential aspects of their identities and the roles they have in life (Charlton, 1998).

One reason for people with impairments or disabilities to take charge of their lives and exercise their autonomy is that some impairments may require prolonged medical treatment. According to Winter (2003) if the medical model were applied, this would require people with impairments to become a patient for life expecting the person to passively accept treatments that were offered with no questions asked and deprived of their autonomy. The SMD thus requires a shift in focus from "cure to care" and that treatment should no longer involve just the "doctor doing and the patient receiving" (Zola & Irving, 1983).

The Consumer/Survivor/Ex-Patient Movement

People with lived experience of mental illness or serious emotional distress have been involved in campaigning for system change and actively transforming the mental health system of care for centuries. During the early 1600s patients at the infamous Bethlehem hospital sent a petition of the "Poor Distracted People in the House of Bedlam (concerned for conditions with inmates)" in order to protest the horrid conditions of that institution (Beers, 1923). Dorothea Dix was believed to experience bouts of depression (Parry, 2006), which inspired her interest in improving the lot of white people believed to be insane. Clifford Beers was institutionalized for depression and paranoia. He wrote of his experiences in his autobiography, *The Mind That Found Itself* (1909) and founded the National Committee for Mental Hygiene organization that has evolved into the national advocacy organization called Mental Health America.

The current consumer/survivor/ex-patient movement (C/S/X)—also called the service users/survivor movement in other parts of the world developed in the US in 1979 with the founding of an ex-patients group called the Insane Liberation Front in Portland, Oregon. Groups such as the Insane Liberation Front began forming around the country during the late 1970s and early 1980s as a way for people who had been institutionalized to begin to make sense of their experiences of institutionalization (Chamberlin, 1990). Anti-psychiatry in the 1960s was a major influence in the ex-patients' movement and helped challenge the claims of mainstream psychiatry. Along with the development of the women's movement, the gay rights movement, the civil rights movement and the DRM, the C/S/X movement emerged with the primary goals of fighting for patients' rights and against forced treatment and stigmatization. Another major goal of the C/S/X movement was to establish peer-run services as an alternative to traditional mental health services, with the idea being that peer-run services would be completely voluntary and absent from the explicit and implicit coercion that exists in most traditional services.

In the 1980s, self-help groups founded on shared lived experience and mutual support proliferated across the U.S (Chamberlin et al., 1996). Self-help programs provided a range of services and activities that included but was not limited to protection and advocacy services, employment assistance, housing assistance, legal assistance, daily activities of living assistance, food assistance, temporary shelter, social activities and transportation. Not all programs provided the full range of services although most programs provided a variety of services.

Both the DRM and C/S/X movements are emancipatory in nature and strive to empower the people involved. Beresford (2005a) highlights several values and principles of the C/S/X movement:

- C/S/X speak for themselves;
- People diagnosed with serious mental illness are people;
- C/S/X do things together (e.g., develop alternatives to traditional services);
- C/S/X have a right to their own say and views;
- C/S/X are not pathological or defective; and
- C/S/X should have a right to regain and take control of their own lives.

Disability discourse is mixed as to whether the C/S/X movement is part of disability studies (Beresford, 2000a). Some prominent texts of the disabled people's movement fail to pay much, if any, attention to madness (Barton, 1996; J. Campbell & Oliver, 1996; Oliver & Barnes, 1998). Some texts include madness but view it through an individual and medicalized model of mental illness in direct opposition of how they view disability and impairment (Gabel, 1999). Still others not only include (McNamara, 1996) argue that the disability movement is incomplete without survivors of the mental health system (Beresford, 2000a).

While the discourse may be problematic at times, it reflects broader uncertainties (Beresford, 2000a). Many people who identify as C/S/X do not view themselves as disabled because it reflects the medicalization of their distress and experience. Some people with physical disabilities do not view C/S/X as being disabled because many do not have a physical impairment or their situation is not permanent (Beresford et al., 1996). From my vantage point as a scholar researcher, I have struggled with my own identity as a psychiatric survivor and whether or not I have a disability, I have managed to figure out ways to mitigate the disabling aspects I experience so that they generally do not show up in public or where they are noticeable to others.

Nabbali (2009) discussed how critics argue that the social model of disability paradigm does not explore the relationship between disability and other social markers such as the voice and plight of mad people (Gabel, 1999; McNamara, 1996; Wilson & Beresford, 2002). Our issues are often viewed and analyzed from a medical model and pharmaceutical industry standpoint, such as the claim that madness is due to a “chemical imbalances in the brain”—despite the fact that the chemical imbalance theory is a myth largely propagated by the pharmaceutical industry (J. Hall, 2013) and many practitioners because of its ease of explanation. When such views are included in the SMD discourse, many people with lived experience of madness will reject it (Bassman, 2001; Morrison, 2003; Whitaker, 2002). The episodic nature of severe emotional distress also makes it difficult for people to embrace a disability identity, as most disabilities have an essence of permanence about them. While some physical and sensory disabilities may be mitigated through technological advances—many are not.

Yet regardless of how individuals with lived experience relate to the social model of disability, doctors, providers, and the larger society see us as disabled. One of the criteria that makes a person qualified to receive accommodations under the Americans with Disabilities Act (1990) is if others view you as disabled. There are other connections—people with physical and sensory impairments are not immune to experiencing serious emotional distress that would cause them to be labeled with a mental illness diagnosis. And still others with physical and sensory impairments developed those impairments due to efforts to take their lives.

An anonymous person (Nabbali, 2009) states:

> [T]he notion of psychiatric impairment is culturally and temporally bound. In other words, the whole idea of being 'crazy' depends on where you are, what time you're living in and who's around you…that's also true for disabled people…if you're looking at somebody in an agrarian society who has a mild development disability and that person is part of a family and works on a farm and weeds and hoses and lifts heavy barrels of hay and sticks them in a truck at the end of the day, or whatever; is that person disabled? Do they have an impairment if, in fact, they are doing whatever is expected of them, earning a living and contributing to the society around them? Then you take that person, you put them in a group home in downtown Toronto, you give them a complicated map and say "Okay, here's your job and read the complicated instructions at the warehouse in the packing department." So does that person now have an impairment?...To apply it to psychiatric survivors, what we are looking at are people who have psychiatric labels. For example, the reason that I ended up in the [mental health system] is because I witnessed a traumatic rape. This was back in 1975. People did not have a concept of what is now called "post-traumatic stress disorder". They did not apply it to victims, particularly female victims, of violence. So when I ended up in the hospital, after the rape, completely like this [motion of distress], they labelled

> me schizophrenic. Whatever! So, to me, that is a good example of the way the social model would apply. The patriarchy created the conditions that put me in the hospital in the first place. If there was no rape, if there was no abuse, if there was no horrendous violence that women experience every day, then we would have these intense emotional reactions, would we?...So what you have is a very clear link between women's oppression in the home or on the street and her subsequent incarceration in psychiatric institutions (p. 6).

Another participant, named Erick, (Nabbali, 2009) argued that the social model of disability is located within mental health consumerism. That is regardless of whether mad people attribute their madness to biology or to other causes, they "are sort of behaviorally impaired in the same way as somebody else being visually impaired. The first sign we noticed that someone is 'blind' is that person interacts differently with society because of the hegemony of sight" (p. 5). Similarly, mad people violate social and cultural mores and it is the behavioral disruptions that become their alleged impairment. "You [consumers] may misbehave because…of some neurological dysfunction. But the misbehavior exists because of social consensus and persists by convention.

Nabbali (2009) participants draw upon the social model of disability in that they address the hardships that occur due to social exclusion, discrimination, stigma and the medical industry that insists every bad feeling requires a pill. The C/S/X movement has pressured policy makers and providers to address the social aspects of mental illness. In an effort to develop an alternative to the traditional medicalized model of mental illness, the C/S/X and user/survivor movements from other parts of the world have identified the intellectual weaknesses and internal contradictions of the dominant "mental illness" framework. These movements have also renewed interest in "social approaches" among stakeholders (e.g., the Hearing Voices Network). C/S/X and service users/survivors also have expressed a growing interest in exploring a social model of madness and distress (Beresford, 2005a).

Social approaches to mental illness are not new to the fields of psychiatry and mental health. Thomas Szasz, R. D. Laing, and David Cooper among others worked to move their fields from medicalized understandings toward more social approaches of understanding (e.g., the role of the family in mental distress) (Coppick & Hopton, 2000; Laing, 1965). However, Szasz, Laing, Cooper and their colleagues never questioned the mainstream concept of mental health. Tyrer (2003) remarked, “All social models in psychiatry have the same fundamental premise. They regard the wider influence of social forces as more important than other influences as causes or precipitants of mental illness” (p. 87). However, most of the anti-psychiatrists did not include the concerns of discrimination, oppression or civil rights in their social models (Beresford, 2005b).

People with lived experience of mental illness are highly cognizant of the discrimination and stigma we encounter every day. We encounter negative stereotyping that results in exclusion from employment, education and parenting. Many of us are required to engage in compulsory “treatment,” and we experience a restriction of our rights in multiple systems including healthcare. The social model of disability provides a framework that can shift C/S/X thinking and action by changing the focus from individual pathology and deficiency to consideration of oppression and discrimination that operates at diverse levels, ranging from the individual to the societal level (Beresford, 2005b).

Some additional clarification needs to be made in terms of the social model of disability and its application to madness and emotional distress. Some individuals who identify as C/S/X do not view themselves as having mental illness. The social model of disability accounts for this perception as an impairment. Others may perceive one as having impairment(s) or in other words that mental illness like impairments are also socially constructed (Beresford, 2005b). Many people who view mental illness as socially constructed may be viewing mental distress "as both a response to and an implicit revolt against, experiences of injustice, enforced loss or abuse" (Tew, 2005). Research on the long-term effects of trauma and intergenerational trauma (Scharf, 2007) are adding credence to this view of emotional distress.

When I think about how I relate to the social model of disability, it does not speak to me in terms of the totality of my experience. However, it is something that is easy to explain to others and I use it as a tool. Even when I felt more disabled and was experiencing frequent hospitalization, the social model of disability did not speak to my experience completely because of my own dance with disability and sanism, also called mentalism by the late Judi Chamberlin (1979, 1990, 2005). Sanism or mentalism describes the discrimination and subjugation that people given 'mental health diagnoses' experience. Perlin as cited in Chamberlin (1990) defines sanism as a

> "prejudice that closely parallels racism or sexism. Sanist attitudes are built upon a foundation of beliefs that are:
>
> 1) Insupportable of valid research and evidence to the contrary,
> 2) Based on "gut feelings" or intuition,

3) Supported by hyper-unusual anecdotes portrayed by the media,
4) Based on how we segregate ourselves (emotions, thoughts, behaviors) from those labeled with a mental disability" (p. 32).

While many people diagnosed with mental illness experience discrimination by both lay people and healthcare providers alike, much of the discrimination I experienced has come at the hands of mental health practitioners and medical providers. Such professionals should 'know better'. Even now that I experience some physical disabilities, I still struggle with the social model of disability.

For people diagnosed with psychiatric disabilities, generally accepted definitions of terminology occur less often—particularly among people with lived experience. For example, "impairment" is often used as a way to describe a person's decisions and or judgment, as seen in the common phrases of "impaired judgment" or "her decision-making capacity is impaired". It also depends on the context and location of what the term means and who accepts the terminology. People who use this type of terminology in reference to people diagnosed with mental illness are most often providers, attorneys and judges.

People diagnosed with serious mental illness rarely use "impairment" in reference to their selves, but find the term used to describe them in their records or used in staff meetings about them. Sometimes, people contest that their judgement was impaired and may have a different understanding of their experience (e.g., a spiritual crisis). We have different ways of identifying and talking about ourselves when we are not well. Some people may use the term "sick". Others may talk about being overwhelmed, anxious or something else entirely. The different terminology we use to describe our conditions and ourselves are also culturally and context-dependent.

A key difference between disability and 'mental health' conversations is that missing limbs and spinal injuries usually do not grow back or repair themselves. But psychiatric labels are unreliable, inconsistent, socially constructed (Beresford, 2005b). People labeled with psychiatric disorders may contest them outright or over time as we decide the labels do not speak to our experiences. Sometimes psychiatric labels (e.g., personality disorders) are arbitrarily imposed on people without a rational basis (Beresford, 2005b).

Dominant Psychiatric Interpretations of Madness and Distress

Many people who use the public mental health system have multiple diagnoses and labels (including myself). These labels are often derived from getting a new psychiatrist or other provider who viewed the symptomatology that was discussed through a different lens from the previous provider. Those of us who are labeled thusly do not experience our lived experiences so discretely. Pembroke (1994) explains,

> "I don't have a *Bulimic* or a *Schizophrenic* day. This definition and separation of the facets of my distress is not helpful. The rigid frameworks psychiatry, psychology, and therapy employ serve only to fragment and objectify people…It was hardly surprising then that some workers found my behavior difficult to relate too…Only certain combinations of behavior were understandable, if they slotted neatly into symptoms 1-6," (paragraph 8, emphasis in original).

Social work, too often, mirrors less-than-helpful practices from other disciplines without critically thinking about the consequences of those less-than-helpful practices thus reifying the social injustices inherited from those other systems. (Poole et al., 2012) argues that "Despite the increasing use of intersectionality and AOP [anti-oppressive practice], social work may [unwittingly] contribute to a pathologizing view of people who live with ‘mental health’ issues” (p. 23).

Sometimes we received additional labels and diagnoses because providers we worked with were stymied by our behavior and did not know how else to help us. Rather than acknowledge that they were stymied; they slapped another label (most frequently a personality disorder label) on top of the other labels. This labeling process made us the problem and further cemented our role as mental patients. Psychiatry and other professions claim legitimacy in the diagnostic process from modernist medicine and science (Boyle, 1999; Wilson & Beresford, 2002).

The conventional belief in psychiatry is that “mental disorders” parallel society’s understanding of physical disorders, which are deemed to occur in individuals and are “discovered” by rigorous scientific research (Caplan, 2004a; Kutchins & Kirk, 1999; Wilson & Beresford, 2002). “Scientific” methods underlie how psychiatrists and others validate certain constructions of “mental disorder” (defining diagnostic categories) and the diagnostic process itself where psychiatrists and others evaluate an individual’s symptoms or signs to establish whether the individual suffers from a specific form of “mental illness”. The *Diagnostic and Statistical Manual of Mental Disorders V* (American Psychiatric Association, 2014) (DSM) serves as a tool for those who diagnose/label others and reinforces the social construction of the disorders included in it as “legitimate” (Caplan, 2004b; Wilson & Beresford, 2002).

Psychiatric Survivor/Service User Research

Strega (2005) argues that marginalized researchers and researchers committed to social justice who are concerned with the inability to bring about social change or increase social equity, should challenge not only traditional research methods but also the ontological and epistemological foundations of traditional methods.

The primary theory behind psychiatric survivor/service user research is the idea that "The greater the distance between direct experience and its interpretation, then the more likely the resulting knowledge is to be inaccurate, unreliable and distorted." (Beresford, 2003b, p. 4). This theory aims to value people who have experienced oppression from the mental health system and society.

Some people may wonder what psychiatric survivor or service user research is. The term *user/survivor* refers to people who use or have used mental health services and/or have experienced mistreatment or discrimination in response to psychological distress or disability (Wallcraft & Bryant, 2003). The Lived Experience Research Network (LERN) states that a "user/survivor researcher is someone who not only has lived experience of distress or disability, *but explicitly uses that lived experience to inform research projects* (Lived Experience Research Network (LERN), 2013; Sweeney et al., 2009).

A primary difference between user/survivor research and "conventional" research is that participants in user/survivor research are partners in developing the research questions, and methods, even when the project *leaders* are themselves users/survivors. Transparency is essential in terms of control and claims grounded in researchers' lived experience. Also, nearly all user/survivor research has the aim to improve the quality of life for people who are or may become susceptible to similar distress and vulnerability. Sometimes this aim is explicit and other times it is implicit.

By contrast, “conventional” research is more hierarchical (Beresford, 2002). For example, principal investigators typically make all major decisions. Often, the data analysis process is not shared with participants or stakeholders. According to LERN (2013) “’Conventional’ [research] often claims political neutrality and objectivity’” (p. 1). Researchers are often more distant and disconnected from the community or population they study than in user/survivor research.

Traditional social research has long valued the ideas of objectivity and neutrality while ignoring the possibility that traditional researchers bring their own values and subjectivity to their research. Studying human beings is different from studying rocks and other physical things—less argument occurs about a rock’s physical characteristics or whether it is of igneous, sedimentary or metamorphic origin. Traditional social researchers are human beings complete with their own emotions and attitudes. How researchers and others understand each other is based on our judgments and values. We all come to our values and judgments through experience (Beresford, 2003b).

The goal of lived experience in research is not to generalize one’s experience to that of others, but to use that experience to become sensitized to lines of inquiry that conventional researchers may never think about, in an effort to improve rapport with participants and enhance the credibility and relevancy of the findings. Although one may have shared experiences with other users/survivors, there is much diversity within shared experiences. Such differences should be considered and acknowledged through the research process (LERN, 2013).

Development of user/survivor research

Psychiatric survivor research developed from the Consumer/Survivor/Ex-patient movement that began in the 1960s and 1970s as people were deinstitutionalized. Many people who had been institutionalized in state hospitals were angry over their treatment and deprivation of dignity and human rights.

User/survivor research is a relatively new area of research and has grown enormously over the past 20 years particularly in the U.K. (Beresford & Rose, 2009). Service user or user-controlled research represents a fundamental shift from traditional research. For example, user/survivor research is usually based on the continuity of survivor action rather than it being a by-product of intellectual trends.

The beginning of user/survivor research mirrored the beginning of the user/survivor movement. Individuals and groups tried to make sense of their experiences, reclaim their identity and have a say in the mental health system (Wallcraft & Nettle, 2009b). Research conducted on the user/survivor movement in the U.K. found that people who identify as survivors or users share many common concerns. However, they also hold many contrasting views on many topics and issues (Wallcraft et al., 2003). Many people, including myself, become advocates in order to prevent future harm to people who are still stuck in a largely non-responsive mental health system.

“Conventional” medical research (including mental health research) relies on a hierarchy of methods and approaches. At the top of the hierarchy are systematic reviews of randomized controlled trials (Type I) with expert opinion (Type IV) at the bottom (John Wiley & Sons, Inc, 2014). Experiences of service users are not included in the hierarchy. Medical researchers typically use the hierarchy as a method to weigh evidence supporting clinical effectiveness. However, many users/survivors find this process to be disempowering (Becker et al., 2010).

Research in the social sciences acts on the belief that classification and quantification are an essential good. Modernist psychological sciences use the operationalization and measuring of hypothetical constructs such as mental states as the only way we can "reliably, validly and objectively come to grips with the world" (Rapley, 2001). Rapley also argues that psychological tests, inventories and questionnaires are "routinely portrayed as essentially *neutral scientific objects* which offer an otherwise unobtainable purchase on any and all aspects of human subjectivity (p. 35 emphasis in original). According to many social-psychological researchers and scholars we can measure people's intelligence, anxiety, depression, and other constructs with instruments that accurately represent the reality of these states of being reliably and validly for all persons. Research tests and tools are used much in the same way a tape measure is used to measure the height of any person against whom it is laid. The height of the person tells us very little about the nature of the individual person. Similarly, research instruments tell us little about the natures of persons to whom they are applied (Sweeney, 2009).

Influences of Psychiatric Survivor/Service User Research

Several influences have shaped psychiatric survivor/service user research: values and principles of the consumer/survivor movement itself; policy; survivor/service user research; and methodology. Key values of the consumer/survivor movement include choice, no coercion, "Nothing about us without us" and honoring the diversity of experience.

Without service users and survivors doing their own research, user/survivor involvement in research would not have happened. For example, (Frank, 1978) researched electroconvulsive therapy (ECT), and compiled an anthology as a way to make sense of his experience. (Campbell & Schraiber, 1989) conducted a survey on well-being of 331 mental health clients in California, an early mixed methods project. The Hill House project demonstrated that people diagnosed with mental illness had the expertise to design valid and reliable instruments (Beresford & Rose, 2009; Prager & Tanaka, 1979; M. K. Smith & Ford, 1986).

The current drive-in mental health services for recovery-oriented services did not come about as a result of "conventional" research. For decades, people who experience extreme distress were told to give up their hopes and dreams, the idea of going to college or having a job and a family by mental health practitioners and researchers. I still remember the times in my life when psychiatrists and other mental health practitioners told me that I would not be able to pursue school, work, or other hopes and dreams. Pat Deegan (1988, 1992), Priscilla Ridgway (1988, 2001) and others conducted or co-led studies on people's lived experience of emotional distress and psychiatrically labeling.

Developing Our Own Epistemologies

Survivor research borrows from early studies on recovery from emotional distress that directly challenges the status quo and “conventional research”. In fact, the idea that people with serious mental health challenges could “recover” came from the consumer/survivor movement rather than from conventional research. Much mental health research is a fairly linear process that typically involves a hypothesis, an experiment, and a conclusion that reflects research results. This type of research often has little influence on what happens in the everyday world.

Researchers who espouse positivist research and paradigms must strive to remove values and subjectivity from the research process. Positivist research may work well when one is studying inanimate things in the physical world. Applying positivist paradigms to social science fails to address structural inequalities and prejudices. Positivist research has been used to support and facilitate bias and prejudice, which has caused great harm to people who are marginalized or oppressed.

Principles and Values

The C/S/X (or service user) movement is characterized by the principles and values of empowerment, emancipation, participation, equality and anti-discrimination (Sweeney, 2009; Turner & Beresford, 2005). Survivor/service user research, a values-based practice (VBP), is an approach to balanced decision-making where complex and conflicting values are involved (Fulford & Wallcraft, 2009). VBP is grounded in analytic philosophy (Hare, 1952) as applied to concepts of disorder (Fulford, 1989). VBP combines analytic with empirical social science research (Colombo et al., 2003) and becomes a philosophy of practice (Colombo et al., 2003; Fulford & Wallcraft, 2009). VBP focuses not just on what is done in research but also on how it is done. VBP "starts from *respect for differences of values* and relies on 'good process'…VBP is similar to evidence-based practice: where evidence-based practice offers a *process* for working more effectively with complex and conflicting evidence, VBP offers a (different although complementary) *process* for working more effectively with complex and conflicting *values*" (Fulford & Wallcraft, 2009, pp. 38-39).

Policy

The U.S. President's New Freedom Commission report is (The President's New Freedom Commission on Mental Health, 2003), one of the more recent driving forces of mental health care transformation, states that "research activities must include a science to services endeavor resulting in delivering the very best-evidence based practices to consumers in a timely way" (p. 72). The report also acknowledged that "In the past decade, mental health consumers have become involved in planning and evaluating the quality of mental health care and in conducting sophisticated research to affect system reform" (p. 37). It recommends that "Local, state and federal authorities engage consumers and families to participate in planning and evaluating treatment and support services" (p. 37).

Policy milestones in the development of user/survivor research include the creation of the Consumer/Survivor Mental Health Research and Policy Work Group in 1992 (Mclean, 2003) under the National Association of Mental Health Program

Directors; and the incorporation of the Massachusetts-based user-led evaluation and non-profit Consumer Quality Initiatives in 2000 (Consumer Quality Initiative, 2007).

Different approaches to providing social services have influenced how services are researched. In recent years, there have been significant changes in how welfare and social services are provided not just in the U.S. but also internationally (Sweeney, 2009). A market-led approach that focuses on individual rights and responsibilities fueled these changes. This approach is referred to as the *consumerist model* (Beresford, 2002; Sweeney, 2009). Core principles of this model include choice, accessibility and information. (Braye, 2000) argues that this model fails to challenge inequities in the distribution of resources, to promote citizenship or to address collective agendas.

However, an alternative to the consumerist model is the *democratic model.* Key principles of this model include autonomy, independence and rights. The focus is on all areas of a person's life rather than their experiences of services (Beresford, 2002; Sweeney, 2009). Major features of this model are compared in Table 7.

Table 7

Comparison of the major features of consumerist and democratic models

	Consumerist Model	**Democratic Model**
Focus	Policies and systems	People's lives and aspirations
Change	Consumers are asked for their input but managers decide whether to make changes	People are both encouraged and enabled to give their input and effect change
Power	'Managerial': managers retain power	'Liberatory': aims to empower groups and individuals
Services	Services are provider-led	There is an interest in user-led and controlled services
Ideology	Treated as unrelated to any overt ideology	Overtly political

Note: Adapted from Beresford (2002) and Sweeney (2009)
Table 7: Comparison of the major features of consumerist and democratic models

Both models have influenced social research. Beresford and Evans (1999) identified two major responses: reactionary and progressive. The reactionary response stresses evidence-based policy and practice; professionals determine which ideas constitute evidence. The alternative or progressive response fundamentally challenges traditional ways of doing research. Concepts such as objectivity and truth are questioned, and lived experience is seen as a valid form of knowledge. The democratic model borrows from Friere (1970). User/survivor research is more closely allied with the democratic model or alternative response (Sweeney, 2013).

Yet, service users and psychiatric survivors question the congruency of many evidence-based practices with recovery-based and person-directed service (J. E. Campbell, 2009). C/S/X often view evidence-based practice as paternalistic and a reflection on the medical model of disability. Much evidence-based research views recovery through a symptom-reduction lens rather than a lens of wellness outcomes such as a meaningful life and hope (J. E. Campbell, 2009; Marzilli, 2002). Fisher and Ahern (2002) make a similar argument: “Currently, the benchmark for evidence-based practices is maintenance: symptom reduction and medication compliance. However, when community integration is used as the outcome measure, the recovery model becomes more evidence-based than the medical model,” (p. 632-633). One service-user/researcher expressed:

> Mental health professionals subsume our identity with a global sentence of illness and disability. It is often presumed that we do not know what is in our own best interests. Our feelings of anger and joy are scrutinized for signs of pathology and violence. Our desires are imputed for us, as if, we were mute. Studies of our everyday lives are routinely emptied of quality, hope and dignity, (p. 17).

Underlying Principles and Motives

Faulkner (2009) identifies several underlying principles of survivor research:

- Clarity and transparency;
- Respect;
- Flexibility;
- Accessibility;
- Diversity;

Clarity and transparency are essential to building trust for collaborative work between researchers and service users/survivors. Clarity about the involvement of researchers and whether they self-identify as users/survivors is crucial. Being clear about the amount and type of influence users/survivors will have on the research is vital.

As it pertains to the thesis, I formulated my research questions as someone who has used public and private mental health services for most of my adult life and who advocates on behalf of people whose practitioners have given up on them. My approach to research comes from years of being or being considered "a mental patient" and being hospitalized more than 20 times for extreme emotional duress. In addition to this experience, I also bring more than 15 years of activism and advocacy for social change in how people diagnosed with mental illness are treated within the mental health system and the larger community. I did not intend to become an activist or advocate but developed those skills because of unjust and harmful incidents that I and others like me experienced in the mental health system.

Implications for Empirical Research on Defining and Measuring Health Literacy

In this era of person-centered care in health care, people diagnosed with serious mental illness are still left out of most conversations about how we obtain person-centered care due to the fears and stigma that many healthcare providers have about *the mentally ill*. Given that some of the symptoms of our emotional distress can, at times, interfere with providing information to providers or understanding and acting on information, it is crucial to understand how people diagnosed with serious mental illness make sense of health information and what facilitates health literacy and builds or maintains health literacy barriers.

Complicating this concern is that when people are worried or concerned that health care providers may "lock them up" or dismiss their complaints entirely, their ability to give, receive and use information is even more challenged. Only by asking people with lived experience will we be able to develop effective interventions and change policies that support people with low or inadequate health literacy rather than add complications to their lives. There is a faulty assumption that people with low or inadequate health literacy do not make medical decisions because they are not able to make decisions.

Related to this faulty assumption, is the idea that people with low or inadequate health literacy will make the “right” decision (e.g., cost us less money) if we increase their health literacy. By talking with people diagnosed with serious mental illness, we may create a more universally accessible health care system that meets people where they are rather than where we would like them to be.

To summarize this section on my approach and understanding of research, this thesis uses a lived-experience framework and approach in deciding upon the methods to identify the health literacy needs of people diagnosed with mental illness. Using my lived experience and the lived experience of others to develop the study design helps ensure that the findings are meaningful to people diagnosed with mental illness.

Chapter Four: Methodology

Study Design

This study amplifies the voices of people diagnosed with mental illness regarding their health literacy needs. Very few studies in the health literacy literature talk directly with people about their health literacy needs. Qualitative research is an appropriate tool for an exploratory study to amplify the voices of people diagnosed with mental illness.

Committee members for this dissertation encouraged me to focus on either the physical or mental health aspects of people diagnosed with mental illness in terms of health literacy. However, after consulting with the project's advisory group and my advisor, and upon careful consideration, I chose to focus on both the physical and mental health aspects of health. As a person with lived experience of mental and physical health issues, I understand first-hand the complexity of living with both physical and mental health challenges. The physical and mental health challenges intersect with each other and have layering effects upon the person experiencing them. People living with mental and physical health conditions do not have the luxury to separate out what part of their body is having health challenges.

I chose to use qualitative research methods, specifically focus groups and individual interviews for people who were unable to participate in the focus groups due to illness or schedule conflicts. Researchers recommend using focus groups when investigating complex behavior and motivations (Morgan & Krueger, 1993). For people with mental illness diagnoses, engaging with situations requiring health literacy may be considered complex behavior. Because there is so much literature about health literacy, I needed to assess where the participants in this study fit using some of the same health literacy assessment tools currently used. Therefore, I added a small quantitative survey to better describe the participants.

Advisory Council

As this is lived experience research, I decided to include an advisory council of people with lived experience of living with mental health diagnoses and physical health conditions. The advisory council consisted of five people who included four women and one man. They all identify as survivors of the mental health system. I has known them for many years as advocates and people who are not afraid to speak their minds and would be able to give me feedback about the research design. These individuals would not be afraid to tell me what they think and tell her if they disagreed with me.

The advisory committee members included Donita Diamata, Scott Snedecor, Christina Treviño, Crucita White, and Angela Wilson. These five people included people who self-identified as Black, Latina, and White. It also included people who self-identified as gay. Some people on the advisory group had a bachelor's degree, some had attended some college, and some had completed high school or had their GED. Sadly, Scott Snedecor passed while I was working on this study.

The advisory committee helped me make design decisions about this study. The advisory group strongly encouraged me to simultaneously focus on physical and mental health experiences and not separate them. The advisory group also reviewed the measures used in this study.

Sample

I conducted four focus groups and an individual interview using purposive sampling. Purposive sampling is often used in qualitative research to identify information-rich cases related to the phenomenon of interest. More specifically, criterion sampling is a commonly used type of purposive sampling in qualitative research (Palinkas et al., 2015). Eligible participants for this study had to meet the criteria of being between 18 and 64 years of age, having a mental health diagnosis, and having used or currently using publicly funded mental health services. These criteria allowed me to access the lived experience of people diagnosed with mental illness.

Recruitment

Potential participants were pre-screened via phone to ensure that they met the criteria for the study. If the participants met the pre-screening criteria, I then met with each participant to review the study details and obtain consent for their participation in the study.

I had significant relationships with multiple mental health providers in the community. Most of these providers had made agreements to help me recruit participants, by placing fliers in their waiting rooms and other common areas. Despite having Institutional Review Board approval for this study, most providers refused to help with recruitment due to fears of liability. Only one provider helped recruit participants in the end. I also placed fliers on Portland State University's campus, in the lobbies of public housing buildings, and on grocery store announcement boards. These flyers yielded few participants. Only one colleague was able to help with recruitment. Subsequently, nearly all of the participants were people who were employed as peer specialists or peer wellness specialists.

I initially disqualified potential participants that I knew. I had challenges recruiting enough people for a focus group simultaneously. In the end, I held three focus groups with people who met the criteria for the study, and I did not know. Given the difficulty of recruitment and after consultation with my advisor, I chose to invite participants whom she knew had lived experience and who also were known for advocating on behalf of people diagnosed with mental illness. All recruitment was completed prior to the Covid-19 pandemic.

Participants

Ultimately, 19 people consented to the study. Fourteen people participated in the quantitative survey. Eleven people participated in the focus groups. Six of the participants self-identified as white females, two participants self-identified as white males, and one person self-identified as a white transgender male. One female self-identified as Native American, and one female self-identified as Black. All participants were between 30 and 64 years of age.

Unfortunately, one of the participants in the focus groups died from suicide several months after the focus group occurred, during the analysis portion of the study. The person who informed me about this untimely death was also a focus group participant. I supported the participant by informing him how to file a report of the death and how to lodge a formal complaint against the crisis center. I also referred the group participant for assistance with peer support and on how to contact his therapist.

In consultation with her advisor, I also filed an "Unanticipated Event Report" with the Institutional Review Board on February 13, 2018. The Institutional Review Board Chair responded on February 16, 2018. The Chair of the Institutional Review Board determined that the event was not serious for the study and non-reportable and that the safeguards were sufficient. The Chair of the Institutional Review Board stated the research could proceed without change.

Consent Process

I obtained informed consent prior to the administration of the online survey and the focus groups. I modeled the consent form after a consent form that I had used for another study I worked on. The consent form had been cognitively tested at an 8th-grade reading level. I did not cognitively test the revised consent form. Instead, she asked participants to state in their own words the content of the consent form. For participants who could not accurately state what was in the consent form, I reviewed the consent form with the participant.

Data Collection

Nineteen people consented to the study. There was a 28 percent attrition for survey participants. Fourteen participants completed some or all of the quantitative survey. There was a 32 percent attrition rate after the consenting process for all focus groups. In all, 14 people completed some or all the survey. Thirteen people participated in the focus groups.

Quantitative Survey

The quantitative survey consisted of demographic questions, a brief health literacy screen (Chew et al., 2004), the Health Literacy Questionnaire (Osborne et al., 2013), and the Recovery Assessment Scale (Corrigan et al., 2004). The Health Literacy Questionnaire was administered twice because I wanted to ask participants to think separately about their physical and mental health care. The survey was administered via Qualtrics Software (*Qualtrics*, 2005).

Focus Groups and Individual Interview

The focus groups and individual interview took place between August 2017 and December 2018. Focus Group 1 and the individual interview occurred in August 2017. Focus Group 2 occurred in September 2017. Focus Group 3 occurred in December 2017, and Focus Group 4 occurred in December 2018. All focus groups and the individual interview were held prior to the Covid-19 pandemic.

Because this study was exploratory, the focus group format was semi-structured, allowing for greater ease, flexibility, and flow of discussion. Focus groups were facilitated by a moderator and one or two co-facilitators, depending upon their availability. The moderator and at least one facilitator had lived experience with a mental health diagnosis. The moderator and one of the co-facilitators self-identified as white. One co-facilitator self-identified as being a second-generation Vietnamese immigrant, while the other co-facilitator self-identified as being Black.

All focus groups were digitally recorded and later transcribed verbatim by me. Focus groups were conducted at Portland State University’s School of Social Work and the Regional Research Institute. Because of the complexity involved in discussing mental health and physical health care, we added 30 minutes to the length of the initially planned focus groups. Each focus group was scheduled for three hours, with a break approximately midway through the allotted time. At the beginning of each focus group, the moderator reviewed the purpose of the study. She reminded participants that they could withdraw at any point in time from the study since consent had been obtained prior to participation in the focus group sessions.

Participants were assured of their anonymity. To help with securing the participants' anonymity, participants were asked to make up a fictional name or pick a color to use for their name. Asking participants to pick a name or a color helped distinguish the participants' voices during data analysis. Finally, the last few minutes of each focus group were spent discussing the participants’ views of the conversation that took place during the focus group and reviewing the contributions of each participant as a form of member-checking.

<u>Focus Group Guide</u>

Participants were asked the following focus group questions with follow-up probing questions as needed.

1. Introduce yourself. Answer the following question in your introduction. If I had a magic wand…I would fix the healthcare system by…
2. Think about the skills, information, and knowledge you need when making medical decisions. Write those things on your paper, and then we'll put them on the board.

3. How do these things (on the board) make a difference when your mental health/addiction issues cause you confusion or distress?

    Probe: What personal things get in your way of getting mental health & addiction support?

    Probe: Think about health care system things that get in your way of getting treatment and support for your physical health care.

    Probe: Think about health care system things that get in your way of getting treatment and support for your mental health and addictions treatment.

4. Think about when you feel distressed and confused. When you need physical health care, what do you need medical providers to know to help you make medical decisions?

    Probe: What do you want your primary care provider to know and do?

    Probe: What do you want your mental health and addiction providers to know and do?

    Probe: If you need to go to the Emergency Room, what do you want the ER staff to know and do?

5. Think about when you feel distressed and confused. When you need physical health care, what do you need medical providers to know to help you make medical decisions?

    Probe: What do you recommend others do when they get confused?

6. Have you ever felt confused when talking with a doctor or other healthcare provider? What was that like? What did you do to get information to help you?

Probe: Have you ever felt confused when talking with a mental health or addictions provider?

Probe: Have you ever felt confused when talking with emergency room doctors and nurses?

7. There is a term called "health literacy" that means you have the skills, knowledge and information you need to make medical decisions about your health care, develop a treatment plan, and then follow the treatment recommendations. What does the term "health literacy" mean to you? Do you think that your "health literacy" is adequate? How does that impact your life in terms of your physical and mental health?
8. Imagine you have just been to a healthcare provider's office. You have arrived home or to the place you usually hang out. You are going about your business. How do you remember to do what you and your health care provider talked about doing?

Probe: We have one last question, but before we ask the last question, can we tell you what we heard you say, and then you can correct us if we got it wrong? (Repeat major points of comments!)

For the last question, what would be the most important thing you would want researchers and healthcare providers to know about what you need to make informed medical decisions about your healthcare?

Health Literacy Definition Used in the Focus Groups and Individual Interview

I chose not to use any of the research driven definitions of health literacy because these definitions were not developed in partnership or collaboration with people diagnosed with mental illness. Instead, when I began the focus groups and individual interview, I explained that health literacy is a concept that describes the skills, information, and knowledge one needs when making medical decisions. Question 2 on the Focus Group Guide asked the participants to identify the skills, information, and knowledge they needed to make medical decisions.

Data Analysis

Quantitative Data Analysis (Reflecting Survey Data)

Given that at least five people who consented did not participate in the survey and at least three people only partially completed it, it is challenging to ascertain meaningful information from the quantitative survey. Additionally, because the overall sample is so small, no inferential statistics could be calculated. At best, only descriptive statistics could be assessed. However, the descriptive statistics of focus group participants could not be isolated from those who did not participate in the focus groups. Therefore, the statistics cannot be used to triangulate the data of the focus group participants.

Qualitative Data Analysis (Reflecting Focus Group and Interview Data)

I used Constant Comparative Analysis (CCA) (Glaser, 1965) for data analysis of the focus group and individual interview. CCA is often used in qualitative research and is associated with inductive reasoning or analytic induction (Lewis-Beck et al., 2011; Silverman, 1993). The data analysis was data-driven rather than guided by theory or a group of theories. The person-in-environment framework was used to reflect upon as the data and themes that emerged. I wanted to amplify the voices of the participants. As a result, I used reflexivity and conversation with a mentor who has done similar research with people with lived experience. This reflexivity and conversations with a mentor, in addition to writing memoranda, helped separate my issues to ensure that the participants' voices remained the focal influence in the findings. I transcribed all of the focus groups and the individual interview.

The data analysis involved five significant steps. I first read each transcript multiple times and reflected upon each one, thinking about what was said and how it related to health literacy. Smith and Shinebourne (2012) discuss the importance of being immersed in the data to keep the participants the focus of the data. Because I also transcribed the data, I heard the data and read the initial reading of the transcripts. Second, I did a line-by-line coding of each transcript. Next, I created a codebook with text examples and quotes associated with that particular code. In addition to creating a codebook, I used reflective memoing throughout the analysis. Third. I read each transcript at least three more times to reflect on the codes and how they fit with the concept of health literacy. Fourth, I then copied primary codes onto Post-it™ notes and placed them on poster paper to help synthesize the data. And finally, I sorted the codes into latent and semantic themes from this synthesis.

Semantic themes are themes that are direct and clear as to their meaning. Latent themes are themes that I interpreted to have those meanings. There are four latent themes in the results of this study: one facilitator of health literacy and three barriers of health literacy. The latent themes are marked with an asterisk in Table 7.

Trustworthiness

To ensure the trustworthiness of the data (Y. S. Lincoln & Guba, 1985), member-checking occurred in two phases. The first phase was at the end of each focus group and individual interview. We reviewed what each participant said during the focus group or interview. The participants agreed that we accurately captured what each participant had said. The second phase of member-check was that I reached out by phone to a member from each focus group to review the findings. The focus group members confirmed that the analysis adequately reflected the interpretation of their experiences accurately.

Saturation

Researchers (Hennink & Kaiser, 2022) found through a systematic review that a common strategy to identify when saturation was achieved was when "little or no relevant new codes or categories were found in data" (p. 3). The researchers also recommend using 'code meaning' to assess saturation. 'Code meaning’ "focuses on reaching a full understanding of issues in the data, its dimensions, and nuances are fully identified and understood" (p. 3).

This study achieved saturation based on these two methods. Overall, the participants’ perspectives were pretty similar. Specifically, there was consensus amongst the four focus groups and individual interviews in terms of the information that they discussed in response to the focus group questions.

Chapter Five: Results

This chapter provides description of the participants, followed by the findings of the study describing the primary themes and subthemes.

Description of Participants

A total of 19 people consented to participate in the study. As aforementioned, fourteen people participated in the focus groups and an individual interview. The majority of participants self-identified as white and female in terms of race, gender, and ethnicity. In particular, one participant self-identified as a Native American female and one participant self-identified as a Black female. Four individuals self-identified as white males. One person self-identified as having two or more race/ethnicities. No participants reported being of Hispanic descent. One person self-identified as a transgender male. The participants were between 18 and 64 years of age. I did not ask them for their specific date of birth or birth year, so it is not possible to determine an average age. Most participants seemed to me to be at middle-age.

Employment Status and Income Source

Most participants were working part- (n = 3) or full-time (n = 5). Two participants were retired. One participant was a full-time student and three respondents stated they were unable to work. I did not query about participants' specific types of employment, but it should be noted that 13 of the 14 participants received peer specialist or peer wellness specialist training from one or more organizations within their state. Peer specialist and peer wellness trainings are a minimum of 40-hour trainings that focus on teaching people diagnosed with mental illness to advocate and support their peers in traditional mental health and substance use disorder organizations.

Seven participants received their income through employment. Three persons reported receiving their income via Social Security Supplemental Insurance (SSI), two participants were receiving Social Security Disability Income (SSDI) benefits, and one participant indicated that they received both SSI and SSDI. One participant preferred not to say.

Education Level

Many participants had high levels of education. Two-thirds (n = 13) of the 19 respondents reported having attended some college. A little more than 40% (n = 8) held bachelor's degrees. Two people reported receiving a certificate at the college level, while one person received an associate degree, and one person had received a master's degree. Overall, the participants had an average of 14.93 years of education, with a minimum of nine years and a maximum of twenty years. One person reported not attending any college.

Visits to a Primary Care Health Provider

Participants' responses to the question of how many times they had visited their primary care provider (PCP) in the past year ranged from zero to seven or more times. Nine participants reported seeing their PCP five or more times in the past year. Four participants saw their PCP two-four times in the past year; while three participants said they had seen their PCP zero to one time in the past year.

Finally, participants were asked to respond to the question of when the last time they visited their PCP was, with responses ranging from less than one month ago to twelve months ago. Six participants indicated the last time they saw their PCP was less than one month ago, five participants declared it had been two to six months since they last saw their PCP, while three people reported last seeing their PCP seven to twelve months ago. Most participants were enrolled in their state's Medicaid program and had a primary care doctor as a result of policies of this state's Medicaid program.

Self-Reported Physical Health Conditions

Participants were provided a list of common health conditions (see Figure 5 on page 130) that people diagnosed with psychiatric conditions might have. Participants were asked to indicate which conditions they experience, (if any). Some participants reported having the individual diagnoses that indicate metabolic syndrome: diabetes, high blood pressure, and obesity. Nearly half of the participants indicated they had back pain. Five people said they had asthma or a lung condition. Three people indicated they had osteoarthritis. Two people described living with stroke and two with thyroid problems. One person indicated having a heart disease and one a sexually transmitted disease. Nine people expressed that they lived with other conditions not listed in the questionnaire. No one reported having a brain injury or rheumatoid arthritis. It should be noted that while no one reported having cancer at time they completed the survey, one participant discussed having previously had brain cancer in the past during a focus group.

Figure 6

Common Physical Conditions People Have

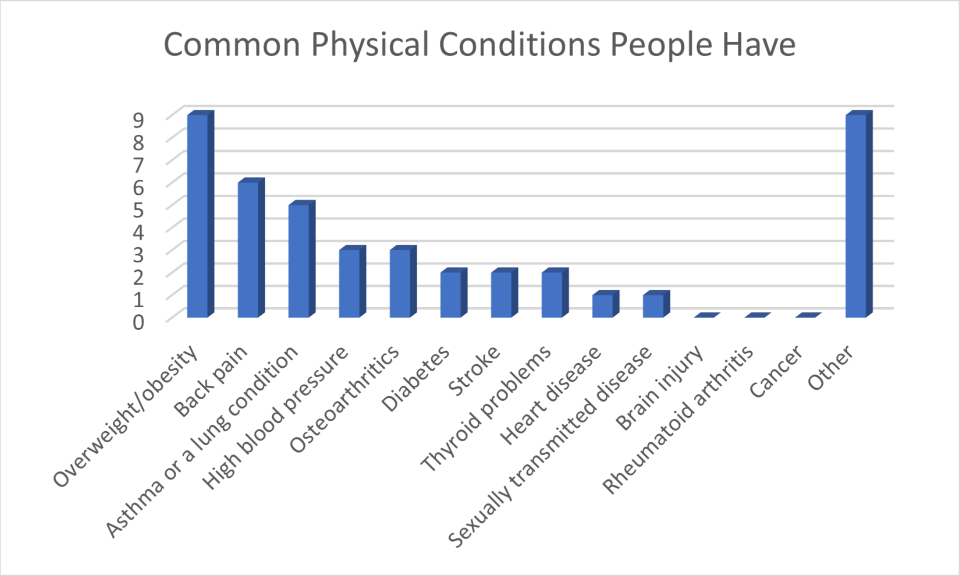

Figure 6: Common Physical Conditions People Have

Hospitalization for Physical Illness

Participants were asked to report how many times they had been hospitalized in the past year. Twelve participants reported being hospitalized zero to one time between 2016 and when they consented to take the study. For most participants that period of time was between 2016 and 2017. For one group of participants the time period was between 2017 and 2018. Two participants said they had been hospitalized two to three times during the past year. I was not able to discern which participants had been hospitalized during a specific time period. I did not inquire about how many participants had experienced recent psychiatric hospitalizations in the same time period.

Mental Health Diagnosis

Participants were asked to self-identify their primary mental health diagnosis (see Figure 7). Eight people each stated that their primary diagnoses were generalized anxiety disorder and post-traumatic stress disorder. Five people specified bipolar II, while four people indicated that their primary diagnosis as major recurrent depression. Three people stated they were diagnosed with schizoaffective disorder; two people reported obsessive compulsive disorder (OCD); one person reported dysthymia as their primary diagnosis; and one person also identified schizophrenia as their diagnosis. Four people reported that their primary diagnosis was not listed.

Figure 7

What Is Your Primary Mental Health Diagnosis?

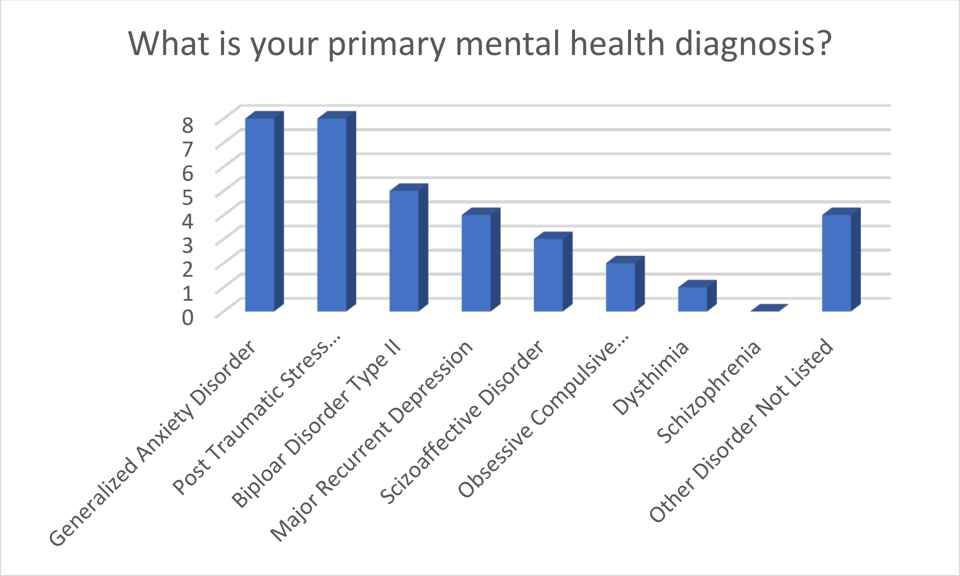

Figure 7: What Is Your Primary Mental Health Diagnosis?

A follow-up question to the primary mental health diagnosis invited participants to self-identify what other mental health conditions they were diagnosed with. This question was open-ended to allow them to self-describe their own conditions. Responses included schizoaffective disorder (n = 2), bipolar NOS (n = 1), bipolar II, mixed (n = 1), personality disorder NOS (n = 1), attention deficit hyperactivity disorder (n = 2), and gender identity dysphoria (n = 1).

Because some people diagnosed with mental health disorders disagree with their diagnoses, I used an open-ended question to ask participants what their diagnosis was. Two people reported different diagnoses than what they had been given. Specifically, one reported that they were a human being with health problems, and the other person said they “don’t believe any of their diagnoses”.

Understanding of Health Literacy

As previously discussed, Malloy-Weir and colleagues (2016) identified more than 200 definitions in their literature review. I believed that choosing a single definition would then limit the responses to that definition and to ideas that support and undergird that definition, which are largely based on vocabulary, reading comprehension, and numeracy, I therefore, elected not to use any of the definitions in the literature, in order to ground the definition in the participants’ lived experience. In fact, no content was generated in the focus groups or interviews that support common definitions around vocabulary, reading comprehension, and numeracy. This may be due to the fact that the participants have a high level of education and struggles with vocabulary, reading comprehension, and numeracy were not foremost in their mind.

In contrast, when queried more directly about basic health literacy concepts, the participants indicated that some of them struggled with some aspects of basic health literacy. For example, I asked participants “How often do you have difficulty learning about your medical condition because of difficulty understanding written documentation?” Of 14 respondents, nine reported that they “occasionally” (n = 5) or “sometimes” (n = 4) had difficulty understanding written documentation, while five of the respondents indicated that they had no difficulty understanding written documentation.

Regarding the question, “How confident are you filling out medical forms by yourself?”, only one person reported being “a little bit confident” in filling out medical forms by themselves. 13 participants stated they were “quite a bit” (n = 7) or “extremely” (n = 6) confident in completing medical forms by themselves.

Participants were also asked, “How often do you have someone help you read hospital materials?” Thirteen participants responded to this question. The response options included “Always,” (n = 1) “Often,” (n = 2) “Sometimes,” (n = 1) Occasionally,” (n = 3) and “Never” (n = 7). In summary, nearly half of the participants had at least some difficulty reading hospital materials and needed someone to help them read the materials.

Some people found it difficult to understand information because of gaps in their knowledge about physical anatomy. For example, one focus group participant noted as a group that [people] “need to know something about the makeup of the body.” Another participant explained how not understanding physical anatomy complicated her recovery from hysterectomy surgery, “I didn’t know enough about anatomy to really understand. And … I didn’t know enough about anatomy to realize how seriously invasive it was.”

The Need to Address the Challenges of Mental Health Conditions and Physical Health Conditions Simultaneously

Participants discussed the challenges of having to manage physical health conditions along with mental health conditions. As seen in Tables 5 and 6, participants commonly identified physical and mental health challenges with which they currently live. It is, therefore, unsurprising to hear and read participants describe situations in which they have to manage both conditions simultaneously. For example, some participants disclosed that they experience high anxiety and heart disease. It is commonly known that people can mistake panic attacks as a heart attack. Other challenges may occur when people experience extreme fear which makes seeking help and trusting others especially people you do not know or are not familiar with to seek help for any physical or mental health condition.

Participants described the challenges of how behavioral health and physical health conditions interact and have a layering effect on symptomatology. One participant stated succinctly, “Our physical health affects our mental health. So, the worse or the better it is, the worse or better our mental health is.” A female participant described in considerable detail her experience of being in labor and having pre-eclampsia and having extreme anxiety.

> My first kid, it was supposed to be amazing, I had planned a water birth. It did not go as planned. I had preeclampsia… They forgot a zero. I was putting out 500 of them, but it was really 5000. They were, like, telling me, you are really sick. You need to go now. And the hospital didn’t tell me anything! Anything at all! And I

> was having a panic attack. And they are just sitting there, like “Turn the lights off right now; make sure she’s calm and get her blood pressure down. Don’t let her family in there!” Even though I was having anxiety, they wouldn’t listen to me and let my family members in the room. It was really weird! They then pushed me to inducing, which I understand I was sick, but I needed my healthcare provided to be communicated with, especially at an intense time like this. Then they proceeded to not listen to me the entire time. The whole thing was horribly traumatic! It caused post-partum depression because of the way I was treated at that hospital! They came in every hour telling me I needed an epidural when I told them no! I lasted 36 hours without that fuckin’ thing! I’m quite proud of that, by the way! Eventually I caved, and I hated it! I kept telling them that I was having anxiety and I was trying to do things to comfort myself. But they would push back with things that they supposedly knew, which was all bullshit! Not letting me walk around, not letting me get into the tub. Things that would have calmed my mental health down which would have resulted in my blood pressure going down. Things that they were resistant towards. And if I had my midwife, it would have went very different because she could have had some leverage. So, I feel like when people with mental illness go into an emergency room, the doctors need to shut up for a minute and let the person explain their problems and what’s going on; and take their medical degree and shove it up their ass for a second! I’m sorry! The person has something they need to say, and you should at least let them try it and see how it goes because it’s not putting them in any imminent danger, there’s no reason to be controlling. Just kind of work out what is helping for the patient with the patient! Not just, this is what my classes told me, this is how it goes, you’re going to do it my way. Because the person is there to receive help! And they need to be receiving help not just being told what to do! It drives me nuts!... When I first started having panic attacks, it was hypochondria. That’s what was what I first had. Every tiny little thing that my body felt, I thought I was dying! So that year I sent myself to the ER a million times. Actually, they were okay. I kind of like [name of hospital]. They would just send me away saying “You have anxiety.” I was so offended at first, I was like there is no way I was just anxious. This has to be real! They were right. I was so horribly offended! But they were right... And some hospitals are really behind the times in trying to keep up to date with patient-centered care.

Facilitators of Health Literacy

As discussed previously, health literacy is a complex construct that includes behaviors or activities that can facilitate health literacy. For purposes of this dissertation, a facilitator of health literacy is any process that a provider uses or a behavior that a service user does that enhances, improves, builds, or promotes health literacy.

Table 8 provides a succinct listing of the facilitators and barriers as identified by the participants of this study. The facilitators of health literacy that participants describe are not well-represented in the scholarly literature on health literacy. All themes with the exception of those marked by an asterisk are semantic themes.

Table 8

Facilitators and Barriers of Health Literacy according to Study Participants

Facilitators of Health Literacy	Barriers of Health Literacy
Positive, long-term relationship with a provider	Coercion and lack of choice
	Lack of trust
Trust	
	Feeling dismissed or disrespected
Treating people with respect	
Listening	Lack of credibility
Asking questions	Lack of trust
Self-advocacy	Diagnostic overshadowing*
Building comprehension and understanding*	Iatrogenic wounding*
	Lack of informed consent*
	Emergency department healthcare

Note: * indicates latent theme
Table 8: Facilitators and Barriers of Health Literacy according to Study Participants

Positive Relationships with a Primary Care Provider

In the close-ended questions, twelve of fourteen participants stated they had a primary care physician (PCP) while two people did not have a primary care doctor. In response to the question concerning the self-reported degree to which participants responded how much they trusted their PCP ranging from “None” to “A great deal”), eight people said they trusted their primary care doctor a great deal, and two people indicated they trusted their PCP a lot. Two people each reported they trusted their PCP a moderate amount or none at all.

In contrast, participants in the focus groups and interview largely did not generate specific data about positive relationships with their providers in either behavioral health or physical healthcare. However, one participant commented:

> If you have a primary care provider who is an advocate for you, it will seem like someone who has a friendly face. It's nice to see a friendly face when everything else is falling apart. Somebody that you trust; somebody that's on your side. Somebody that's willing to be patient. Somebody that doesn't get frustrated easily.

Participants did, however, identify some specific behaviors that fostered positive relationships.

Treating People with Respect

Respect seems basic and should not require much explanation. However, participants regularly suggested that listening and a sense of trust are essential parts of treating people with respect. One participant was rather blunt in their recommendation, "treat people like they are human. Not their diagnosis, not what they are coming in to be seen for, not because they are agitated. So, you treat them in a way that's very disrespectful. Just treat them as human beings." Another participant stated that, "I like to know that people are talking to me and not down to me and some sort of emotional/social intelligence because I have that. I don't expect to be talked to in a different way."

Another participant commented about the contrast in respect that she felt by obtaining services from a culturally specific provider. She describes the differences of a traditional mental health services clinic and a culturally responsive provider.

> I think it was when I started going to [culturally specific provider]. The level of respect was different from anything I had ever experienced before. The fact that they would ask you how you felt about this or that, and they had groups to sit around and laugh and talk like the diabetes group, and the "Let's Go Walking Group" or whatever that we felt a sense of community. Part of some of the issues in my life was having a cultural identity crisis because my tribe that I was a part of was terminated in the 1950s and I was born in the 1960s. I had a little you know what do they call it—identity crisis most of my life. To feel like I belonged somewhere was an amazing feeling! It didn't matter what tribe you were; it didn't matter what percentage of blood you were. They were just accepting even of people who weren't native. We had these problems and we were going to work on them together. They had the most amazing doctor there—I think she was a nurse practitioner but everybody loves her. I don't know how she has the energy she has. It's clear when you go in there, it's not a huge health care provider. It's a very small close place where you kind of get to know everybody, and there is a lot of respect. When you look at the statistics on health disparities in an ethnic population and guess what, most of us have diabetes. Guess what? Most of us have been suicidal before. We've had addiction issues. It kind of becomes a place where you belong and then being with respect! It's nothing like going to an Emergency Room! Your treated with respect there and because of that you do feel like you can ask questions.

Listening

Listening, taking care, and being intentional, not trying to prescribe, and offering some reassurances are a part of listening as opposed to requests that are compliance-oriented. According to participants, providers who took time to develop positive relationships with them helped facilitate their health literacy by listening to them, as this participant explains:

> People should actually be listened to, because it usually has some grounding in reality, somewhere, even if they're from another planet, they're referencing their home world. It still is something useful for them to know. They also need to not be judgmental. They need to understand they don't know everything. People are there to benefit from their experience and education.

One participant described how patients know themselves best. She then went on to tell the story of someone who was addicted to heroin. A healthcare provider asked him what he needed to get off of heroin, and he replied, “socks.” She said that person got off of heroin because someone gave him a clean pair of socks. She concluded by stating, “It’s very disrespectful for a professional to think they know more about me than I know about me. And as a professional, I’ve been guilty of that, but it is very disrespectful.

Another participant spoke about how her mental health provider listened to her the day she was fired from her job. She doesn’t remember her mental health provider saying anything specific but talked about how he listened to her when she was having such a difficult time and she attributes his willingness to listen to her to her not developing additional symptoms of distress.

Several participants commented how listening was essential to building a trusting relationship and specific things healthcare providers can do to help calm someone experiencing extreme emotional duress.

> If they [the provider] can calm their voice or slow down what they are saying to demonstrate that they care. Asking people about basic needs such as “Can I get you some water?” “Do you need to sit?” “Can I get you anything?” Just a couple of little cues like that might help people calm down and be more receptive to participating in listening and being a valued partner in their care. That’s a really good skill set that they had knowledge of and had capacity for and was built into the expectations of the daily schedule or whatever.

Still, another participant went further in discussing the importance of not rushing people and being understanding when people have ‘flipped their lids.’[3]

> Don’t rush me out of…give me my time like, make space. Allow the person to have their process. And they need to know they first got to build, once again, a rapport, they have to build a relationship with the person. That’s really important. It’s important for me. If I go in, and I’m um, I’m gonna say my lid is flipped, it’s going to stay flipped, especially if I don’t know you and I don’t trust you. Right? I don’t think you’re listening. I don’t think you’re able to hear me, right.

Facilitate Comprehension and Understanding

Helping people understand what is happening to them helps facilitate their comprehension and understanding—which are essential attributes of health literacy. This is the only latent interpretation of the themes organized under facilitators of health literacy. Checking in with them to see if “yes” really means yes, and “no” really means no is part of facilitating comprehension and understanding. Several participants described behaviors that medical providers did that facilitated their comprehension and understanding. For example, one participant described, “She takes time with me; and if I have questions, she answers them. She explains things in a way that I understand, and she lets me ask questions. She’s pretty good. I like my doctor.” Still another participant praised her primary care doctor saying, “She will explain things to me in plain language. It can’t get any simpler than that.” Another participant described how her doctor provided reassurance to her when she had the flu:

> …you need to stay inside, and drink lots of fluids. There’s not a lot you can do. If you’re feeling really, really sick, then you need to go to the Emergency Room.” Sometimes, I just need to know there is a flu going on. Sometimes, I just need

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[3] This participant was referring to a YouTube video where Dan Siegel, MD, describes “Flipping Your Lid” for children who are emotionally distraught. See https://www.youtube.com/watch?v=G0T_2NNoC68&t=99s

> reassurance. It's not some awful thing that is happening to just me. Sometimes I just need to know that.

What Participants Recommend to Build Their Health Literacy Skills

Self-advocacy

Participants discussed the importance of self-advocacy in building health literacy skills. One focus group developed a list of specific skills that they felt people with psychiatric disabilities need to build their health literacy skills, to which they all agreed. This list included the following skills: knowledge of physical anatomy, knowing how to get knowledge of treatment options available to you; knowledge of different types of healthcare providers (e.g., not very many people know what and or naturopathic doctor is), people need to know about themselves (e.g., their diagnoses so that people know which questions to ask; computer literacy skills to research clinics and options for your condition, and a phone and enough patience to navigate a phone tree.

This same group of participants also noted that self-advocacy involves risk and that people, particularly with psychiatric disabilities or perceived mental illness, can be punished by being denied resources or even losing their liberty through the processes of civil commitment. People from all of the focus groups and interviews discussed how much more difficult self-advocacy is when they are not feeling well.

Participants in all of the focus groups also identified one or more of the above factors as being important to self-advocacy, as reflected by this focus group member:

> I think I need…to think about what um, to know what the…what the long-term consequences are gonna' be. Like right now, I'm dealing with a medication with a lot of questions about my meds. And... I'm frustrated that the psychiatrists don't tell you about the risks about a particular medication. I ended up hearing a story about someone who died from taking a med I take; well, no a med like it, lithium instead of Depakote. So, I called, I emailed my doctor and I said, "Could you

> order a liver test?" and he said, "Of course." It sounded like he was saying, "I want to know if you're healthy or not." But I had to request it.

Some participants discussed that part of self-advocacy includes educating medical providers about their conditions. As one participant described, "I end up educating my providers." Several other participants in that focus group nodded their heads in agreement with that comment.

Participants also discussed the difficulty of advocating for oneself when they do not feel well. They recommended asking trusted family members and friends to help advocate when necessary.

Ask Questions

Some participants discussed that part of self-advocacy includes educating medical providers about their conditions. As one participant described, "I end up educating my providers." Several other participants in that focus group nodded their heads in agreement with that comment.

Participants also discussed the difficulty of advocating for oneself when they do not feel well. They recommended asking trusted family members and friends to help advocate when necessary.

> Knowing when and what questions. And then you have to know, like, well, that's an advocacy thing. So, so, if a doctor prescribes something, and you have a side effect, then they call and say, they say take this medicine for two weeks, [undiscernible]…so you go home and take it and you can't get out of bed, whether it medical or mental health medication, you need to know how to come back again. And decide…some of the nuances in social interactions to understand, cuz here's this person in authority, and they're telling you to do something, and they're the expert, and you know it's doing something different. And you need to rise above that and question somebody in authority to get your needs met.

Barriers of Health Literacy

In contrast to the facilitators of health literacy, there are activities or behaviors that impede health literacy. Participants identified several behaviors and activities that they felt negatively impacted their health literacy. For purposes of this dissertation, a barrier to health literacy is any process that a provider does or a behavior that a service user does that impedes, hinders, or thwarts health literacy. As with the facilitators of health literacy, the barriers of health literacy are not well-represented in the scholarly literature.

Coercion and Lack of Choice

Coercion and lack of choice occur often in healthcare settings. Coercion can occur passively or more directly. Lack of choice occurs often in the healthcare system. Lack of choice can be about choice of providers (especially if you live in a rural or frontier region) or it could be a lack of choice about specific treatments. Coercion and lack of choice can contribute to a lack of informed consent.

Participants discussed coercion and the lack of choice in the context of providers and treatment options. Coercion and a lack of choice contributes to iatrogenic wounding (but is not the only way in which iatrogenic wounding occurs), and impedes people using their health literacy skills. This participant shared that she was extremely frustrated that she could not have a different mental health provider:

> My problem is I hate my mental health provider at the clinic I go to. I do not want to be going there. I did not want them as my clinician. I agreed only to go there because that’s where I wound up and I had no other choice. That’s where I wound up. I had no other choice. That’s where I wound up. I like my counselor. But as far as the clinic goes, I don’t want to be there. My prescriber is good. My

> counselor is good. But I don't want to be at the clinic that I'm at. It's out of my hands.

Regarding whether one could access alternate treatment options this participant used this metaphor:

> Even a car wash has more options than a doctor's office. You go in and you go in and they say; "Ok, take this too." They don't say, "We could do this, or we could do this, or we could do this, or we could do this, or we could do this.

Another participant described the barrier of being stuck, which means that she is not involved as much as she would like to be in her treatment plan. When people are not involved in their treatment, they are less likely to follow treatment recommendations. While there are many other reasons for not following treatment recommendations, one possible consequence is that current treatment issues may be exacerbated requiring urgent or emergency care and higher levels of treatment. Involving people in their treatment plans that address their goals encourages people to follow the treatment plan because they have had some say in the development of the treatment plan. A participant described her frustration with not being involved in her treatment plan, she offered:

> [Sigh of frustration] I don't think I really develop, I'm not involved as much in developing a treatment plan as I would like to be. I think they pretty much do it for me. I'm not involved as much as I would like to be. It is then my choice if I follow the treatment recommendations or not but because I'm not involved in the treatment plan; I don't always follow the treatment recommendations because I don't always agree with them. So, if they don't include me in developing the treatment plan, then if I don't agree with it, then I don't follow it.

Lack of Trust

Lack of trust can occur when people do not feel listened to or heard. Lack of trust can also be based off of previous experiences with a particular healthcare provider or healthcare providers. When people do not trust their healthcare providers, they are less likely to ask questions to use the health literacy skills they already possess. The lack of trust in healthcare providers can have a polarizing effect. People may react passively and obtain treatment for the immediate future and then not follow through with other treatment recommendations. The other common reaction that people can experience when they lack trust in their healthcare providers is they become antagonized and irritated.

Study participants expressed that they generally do not trust healthcare or behavioral healthcare providers because of prior bad experiences and experiences that they have helped other people with psychiatric disabilities navigate. This expression stands in contrast with most participants' earlier statement that they trust their *specific* primary care providers. As one participant stated, "It took me a long time to find a good doctor. It took me a long time to find someone who I trusted." Another participant commented:

> But I found with being assertive and not aggressive, but assertive and not always just complying. That's when they throw things like "noncompliant" or "borderline" or "personality-disordered individual." That tends to land on people who make a noise or trouble. I've seen it. I know what kind of talk goes on behind closed doors. I've been a member of interdisciplinary teams. They go in the back and talk about people. They say horrible things about borderlines and other people. I was in the closet all those years.

Another participant described an unhealthy relationship with a mental health provider that caused him to distrust the relationship and possibly jeopardized his recovery journey:

> She [participant's mental health worker] had been sick a lot. Then her mother died and so she came into all this money and they bought a house at the coast. She's was always at the coast missing my appointments or I was sick and missed my appointments. I hadn't seen her for at least four weeks. I asked her [via text] at 1:30 and my appointment was at 2:00 if she would be in the office today. At 3:00 when my appointment was supposed to be over, she texted me and said, "Yes." And then I called her on the phone, and she said that she was with someone, and

> she couldn't text or talk on the phone. Well, that was my time. From 2:00-3:00 was my time. And she was with someone else. Probably with her 1:00 appointment. I wasn't going to drive all the way across town in the heat and the cost of gas just to find out that she's not in the office because that has happened before. She said, "I think I'll start putting people on a call list, and if I have a cancellation, then I'll call them." Then she said, "Can you come now?" I explained to her that I had another commitment and I didn't have time to come now to see her. My appointment was at 2:00." Then she [the counselor] put her administrative assistant on the phone and she said she had texted a reminder to me. Well that was a lie. That wasn't even the issue. I knew I had an appointment today. I knew it was at 2:00. I just wanted to make sure she was there. And she didn't bother saying yes, until 3:00. A couple of weeks ago, I drove there [to the clinic for his appointment], and she wasn't even there. It's a big part of my day to get myself ready to go, and drive across town do therapy and come home. It takes up most of my day. I have a really hard time getting out of my house.

Feeling Disrespected or Dismissed

Healthcare providers can cause service users to feel disrespected or dismissed through actions, comments, and other behaviors. People may have polarized reactions when they feel dismissed or disrespected. In the case of some of the participants, it caused them to passively accept services. For others, it antagonized them, and they become angry. Feeling dismissed or disrespected connects to health literacy in that these feelings frequently impeded communication with healthcare providers. Several participants discussed feeling dismissed or disrespected by providers in behavioral healthcare and physical healthcare settings. Participants who didn't speak directly to experiences of feeling dismissed or disrespected nodded in agreement with the participants who were speaking directly about feeling dismissed or disrespected. These participants reflected on their experiences of discrimination and stigmatization. As one participant emphasized:

> Before I became a social worker, I was in med school and I had to drop out because of my illnesses and I couldn't do it. That's [having training] isn't always a guarantee that you will be treated well. You could have all the knowledge you want. You could have a billion letters after your name and you can still be treated that way [disregarded, disrespected, and dismissed].

One of the consequences of feeling disrespected and dismissed is a variety of negative emotions and emotional reactions such as anger and frustration, as this female participant illustrated in her comment:

> Even today, every degree you can get and licensing, and what society says is what normal people are supposed to do; it doesn't count for anything. I have no credibility. They just flat out don't believe me. I have chronic pain syndrome. I said, "How can it be chronic? You have never treated it." Zero drug history, zero alcohol history. I mean I have never touched the stuff. Ever. "We don't want you to get addicted." "We don't want to make your schizophrenia worse so we're not going to treat your pain. So, it's constant pain…as a result there's too much stress.

Lack of Credibility

The lack of credibility occurs when people lose control of their narrative. Healthcare providers rewrite a person's narrative through their charting. Other ways that people lose credibility with their providers is when a provider does not believe what participants have to say. When one is viewed as lacking credibility, healthcare providers do not take your concerns seriously. When one lacks credibility as a reporter of one's own story, this impedes overall communication. Healthcare providers may not take time to discuss your current health conditions; one is at risk for forced treatment; and some health conditions may not get addressed because one lacks credibility.

Being viewed as a non-credible reporter of information about oneself is closely related but also different to feeling dismissed or disrespected. One participant was rather blunt when she said, "Believing you is a good start." All participants in this group agreed with her succinct statement. Participants in the other focus groups shared this sentiment, too.

Some participants alluded to the possibility that those who have mental health diagnoses that are more stigmatized than others (e.g., schizophrenia) may also be more likely to be viewed as a non-credible reporter of their own experiences. One participant diagnosed with schizophrenia commented they used to be a member of a sports team until they had a heart attack several years ago. They stated, “If I could change something, that experience when I started seeing doctors and physicians… that’s when all of the labels started rolling in because I have a diagnosis that is still fairly stigmatized…that put me in a position with no credibility.”

A participant described the potentially devastating consequences of not being viewed as a credible reporter, feeling dismissed, and disrespected:

> …if you’re compromised in some way, you’re at the mercy [of the system and the people who work/run it]. I’ve had other people in charge of my life. I’ve ended up in hospitals for sometimes two-three years at a stretch. I’ve had electric convulsive therapy; drugs…

Medical and behavioral healthcare providers can be judgmental at times. Being judgmental is another form of iatrogenic wounding. One participant described some of the cruel words that some providers have told her:

> …there are people out there saying that, “You know what your problem is? You don’t think the rules apply to you” when there are people out there suffering just seems overprivileged and wrong. I need to understand. It took me years—I’ve been in therapy for years—over 10. It took me years to figure out why my life was the way it was and why I didn’t make decisions. I grew up with men beating me for many, many years and telling me what I liked and what I didn’t like and all this.

Diagnostic Overshadowing

As noted in Chapter two, diagnostic overshadowing occurs when clinicians attribute whatever symptoms or complaints a person has to another diagnosis or condition such as a mental health diagnosis or intellectual disability (Jones, et al., 2008). This is a latent code. Participants were not familiar with the term diagnostic overshadowing; however, nearly all were able to describe one or more instances when they had presented for treatment of physical illnesses that had been viewed as part of their "mental illness."

The experience of diagnostic overshadowing created barriers to health literacy because participants did not have accurate information about their health conditions. Participants also suggested that they faced barriers in identifying which questions people should ask about their healthcare. For example, one of the participants described the following situation:

> I need them to not judge my anxiety disorder. I feel like that's important because or just listen to me in general. So many doctors don't pay any attention. I had multiple emergency rooms in [city] misdiagnose kidney stones for eight months. Eight months! And no one, nobody found it or listened to me! They kept giving me antibiotics after antibiotic thinking I was being overdramatic because I had anxiety and because whatever! It was just stuck in there for eight months! So finally, it came out. Finally, I had [name of medical center] give me a proper scan and put the injection with the dye, yeah and do a proper scan. They said, "Well, you have a giant kidney stone, that's like seven millimeters! Most people don't pass over five millimeters. That's why you've been hurting!" For almost a year! It was stupid! And so, they need to be listening to patients when they're trying to communicate instead of pushing them around and giving them antibiotics and…yeah, and give them proper follow-up care. It's really frustrating!

Another participant described a similar experience that had potentially life-threatening consequences:

> I had a doctor who saw that I had a swelling on my leg that was quite visible. He said that it was just a fatty lipoma. [I kept saying], "No, no, I'm feeling circulation issues or something's wrong and this went on for a month or more. Finally, a

> different doctor, a foot doctor said, go get this checked out and was able to pull the right strings to get me checked out. It turned out to be a blood clot that could have been a real danger to their overall health. The doctor didn't really want to assume that it could be that much of an issue because the doctor knew I had mental health issues.

Another participant described how a condition went undiagnosed for several years causing significant life challenges for them. They noted:

> …despite multiple hospitals and multiple specialists, nobody could figure out the individual's condition. The professionals kept saying it was idiopathic or unknown. Then, finally, a rheumatologist came into the room and diagnosed the person within five minutes and got them started on a treatment. The individual had complete remission.

Iatrogenic Wounding

Iatrogenic wounding is when the healthcare system or its workers cause a person harm. This theme is a latent theme. Iatrogenic harm connects to health literacy because it can cause people to avoid healthcare at great cost to themselves, it makes people less likely to trust healthcare providers or believe that healthcare providers have their best interest at heart. When people who experienced iatrogenic wounding do seek healthcare, they are likely to be guarded in what information they share, may not ask questions or share other important information.

Participants described multiple instances of when they had been harmed by the healthcare system (physical and behavioral) or healthcare providers (physical and behavioral) that made it difficult to form positive relationships with subsequent providers or trust that the healthcare system was a resource that could address their concerns and complaints. For example, participants discussed reading their records and finding gross inaccuracies in their records. As one participant explained, "My neurologist has that I weigh 215 pounds. Right now, I weigh about 154. On my chart it says that I weigh 215." Another participant opined, "Have you ever read the psycho-social histories they take of you and wonder, 'Wow, I wonder where they got that?'...They said I grew up in Ohio. I asked them where they got that and they couldn't tell me." These concerns may seem minor to many people. However, some medications are prescribed according to weight a 60-pound weight error could be potentially life threatening. The failure to care that the accurate documentation of where a person grew up is a larger sign of the lack of care and concern that people have experienced in the healthcare systems.

Failure to listen

Another form of iatrogenic wounding also occurs when providers fail to listen to people. Participants discussed multiple times the failure of healthcare providers listening to them that it warranted a category of its own. The participant that had kidney stone for eight months was not listened to. The participant that had a swelling on her leg was not listened to. The woman who was in labor with pre-eclampsia and anxiety was not listened to. One participant described a mental health counselor working an overnight shift on the crisis line when a woman had just been given a terminal diagnosis of cancer. He described how the counselor was just "phoning in his performance".

> …you could tell the person [crisis counselor] was doing all of this reflection "How does this make you feel?" [chuckling by the group accompanied by eye rolls] and you could just tell the other person [crisis counselor] just wanted to go back to sleep. We used to call them "cardboard." It's like talking to a piece of cardboard. Like a cutout of a human being because there's nothing warm or emotionally satisfying because you are always getting these kinds of responses…

Lack of Informed Consent

Healthcare providers are required to obtain consent prior to beginning any treatment. Informed consent helps increase patient safety which is a part of health literacy. It also helps people know what conditions they are being treated for and what treatments that have been prescribed for them. Informed consent consists of being told what treatment is being prescribed, the risks and benefits, and what alternative treatments are available. Nearly all the participants had stories about how they felt they had not been given informed consent especially around psychotropic medication. Participants were also frustrated with the lack of informed consent in general, but specifically around psychotropic medication. Participants described not being told about the long-term effects of psychotropic medication. Some participants described having gained significant weight on psychotropic medication. However, it is just in the past 10-15 years that behavioral health providers have expressed any concern about people's weight gain.

> I only recently learned that I'm not using insulin very well and it's caused tremendous weight gain. I was talking with my doctor about this and I don't like to lose composure but I told her I felt like you should have told me that! I already have a weight problem. "Why didn't you tell me that?" They weren't doing this in the 80s when I was taking all those super heavy drugs like Stelazine and all that, Thorazine, and everything beyond that. Yes, that's going to destroy your metabolism. It's going to cause diabetes. It's going to destroy your heart. I understand what they're saying. I have enough background I can get that. I know the lingo, but what I need is more of a bigger picture! If you take this kind of stuff for 34 years, this is what your body is going to look like. I need to know that. I did not get to make informed decisions about psych drugs, insulin, steroids, any of that.

Several participants expressed agreement that they feel they do not receive full informed consent when it comes to psychiatric medication. Some participants described having gained significant weight on psychotropic medication. However, it is just in the past 10-15 years that behavioral health providers have expressed any concern about people's weight gain.

Emergency Department Healthcare

Finally, the challenges of all the other barriers to health literacy occurred in study participants' experiences of the Emergency Department. Multiple participants said that they avoid the Emergency Department given that they view it "like the plague" In contrast, participants said they only go to the Emergency Department when there is no other alternative. Several participants described situations in emergency departments that created barriers to health literacy or to people feeling they did not the ability or desire to use their health literacy skills. For example, this participant described feeling threatened:

> I'd gone to the Emergency Room scared of my [brief pause] symptoms. But not…I've had people bring…Well, let's see…a long time ago, I think a boyfriend dropped me off at the ER and it was [name of facility] and I was terrified by my thoughts and I [brief pause] remember going into the room that they interview you in and telling them, talking about what kind of voices I was hearing. Like, whether it was a female or mail voice? Or…were they inside or outside of my head? And…it was…I was alone, you know. There wasn't anybody. Except the doctors. It was really scary, but…[unintelligible]. Oh! And the worst thing was in that hospitalization, …they decided to put me in the hospital and a nur…a male nurse said to me, "Do you have any legal problems?" And I said, "No." And he said, "Well, now you do!" I was like, [made confused facial expression]. "You're burned out man!" Because what he was meaning was that they were going to hold on to me [putting her on a notice of mental illness]. But that is not what people usually mean by that. It was soooo negative, I was like, "Fuck you!" You know. I don't need you around me! So., yeah…I haven't always had therapeutic interactions when I've been confused and scared. Sometimes, you get providers who are burned out and say stupid things. It hurts you.

This participant noted that she had already been scared and feeling alone. She further noted that the nurse responded to her in a way that did not provide clarity or help the participant deal with being scared and alone; and the symptomatology that she was experiencing created barriers to using what health literacy skills she had or for her to learn additional skills at that time.

Another participant noted the contrast in receiving care from a culturally responsive provider and the Emergency Department. She commented:

> …It's nothing like going to an Emergency Room! You're treated with respect there [culturally responsive provider] and because of that you do feel like you can ask questions. You do know what's going on because they explain it to you. They ask you if you do understand. They ask you what you think/feel about it.

Still another participant discussed how she avoids the emergency room:

> What I think of the emergency room is that I think I've been to the Emergency Room when it was my idea just once or twice. I just don't go to those places. On the occasions that doctors have said I want you to go to the Emergency Room, I get there and then I get, "What are you doing here?" And then I get the label. For a while there, I was like a "frequent flyer" even. I finally turned it around in my mind and I said, "No! I'm not doing that anymore! It's a waste of resources. I get stuck with a label I don't want." Yep. Nope!

Participants described how physical symptoms can mask mental health and substance use problems. Specifically, one participant discussed how she had been sick for several days (involving repeated throwing up and diarrhea for days) because she had run out of her psychiatric medication and had not been able to get to the pharmacy for days because she was so sick. It took talking to her therapist while she was in the emergency department to figure it out.

> I hate going to the emergency room. But I had been so stressed out but I didn't relate it to stress. I was throwing up and having diarrhea for days. My friend said, "We have to get you to the hospital!" They said, "What's wrong with you?" I'm telling them… "Well, because I had been sick, I hadn't gotten my refill on my medication". And so, then I started bawling, and I felt incredibly sad. So, I was talking to my therapist on the phone and the doctor comes in and says, "What's wrong honey?" [in a high-pitched tone and grimace]. And, I'm like, "I think we figured out the problem. I've been off my meds for a couple of days because I've was so sick I couldn't get to the pharmacy. We got it all together. But then I had to have somebody come and give me a ride home and all that. They didn't know

if I had the flu or what. They’re not always…the last place on earth I would want to be is the Emergency Room!

Chapter Six Discussion

This chapter discusses the study's significant findings, reviews the limitations, and identifies future needs for researchers focused on the intersection of health literacy and people diagnosed with mental illness. It also offers implications for social work education and practice.

The central research questions that guided this study include

- What are the health literacy needs of people diagnosed with mental illness in physical and behavioral health?
- What are the barriers and facilitators of health literacy?
- How does health literacy impact people with psychiatric disabilities in physical and behavioral healthcare? and
- How can healthcare providers (physical and behavioral) address the health literacy needs of people with psychiatric disabilities?

These research questions matter and reflect the importance of directly asking people with psychiatric disabilities about how health literacy impacts them and how they navigate the health care system regardless of their health literacy status is. As specified in Chapter three, people with psychiatric disabilities are the best experts on themselves in terms of identifying their needs.

As elaborated in this chapter, this dissertation calls into question the way health literacy is currently understood and researched to date. The extant research views health as separate from mental health, as health literacy as a static concept, and as operating within the person as a state or trait. In contrast, I argue that health literacy must integrate health and mental health and be holistic, culturally responsive, and trauma informed. Health literacy is a dynamic rather than static condition; and is a relational process rather than an attribute that resides in the individual.

Summary of Methodology and Results

This study was a qualitative study with a small quantitative survey. The major aspect of this study involved four focus groups and one individual interview. A central theme that emerged in this study is that people with psychiatric disabilities live with both physical and mental health conditions simultaneously. These conditions have a layering effect upon each other. Facilitators of health literacy included positive relationships with healthcare providers, treating people with respect, and listening. Many participants described behaviors that healthcare providers did that facilitated their health literacy such as using pictures to explain things or talking to the person in plain language and providing reassurance.

This study used a lived experience and mental health survivor approach and framework. To my knowledge, this is the only study on health literacy that has used this approach and framework. An essential difference between this study and many of the health literacy studies described in Chapter two is that we consider the knowledge and life experiences of the participants as assets and knowledgeable sources of information. In specific, many prior studies viewed people with low health literacy as a problem.

In contrast, I am not shying away from the challenges of low health literacy, but rather am embracing them. People with low health literacy and psychiatric diagnoses make healthcare decisions every day. This study, therefore, aims to improve the healthcare experiences and quality of life of people with psychiatric diagnoses. This viewpoint may result in added benefits to the system—and it is precisely this viewpoint that makes more research with people with lived experience a necessity.

Participants had several ideas for building their health literacy, such as teaching self-advocacy skills to their peers. While discussing the necessity of self-advocacy, participants also acknowledged that self-advocacy involves risk. The risks involved with self-advocacy include being punished by the denial of needed resources or even the loss of liberty through the processes of civil commitment. They also identified the following skills that people with psychiatric disabilities need to improve their health literacy skills: knowledge of physical anatomy, knowledge of the different types of healthcare providers, knowledge of how to find available treatment options, and knowledge of their particular diagnoses so that they know which questions to ask. Participants also identified technical skills, such as computer literacy skills and patience to navigate phone trees.

Study participants identified multiple facilitators and barriers of health literacy as they understood them. The facilitators and barriers they identified are not well-represented in the current health literacy literature but appear more commonly in healthcare quality literature. The barriers and facilitators that study participants identified relate closely to those of black people accessing mental health treatment in their communities as discussed in the Ayalon and Alvidrez (2007) study.

This study’s participants differed from most public mental health clients because they were well educated. Nearly all survey respondents had attended at least some college, and more than 60% held a bachelor’s degree. One other significant difference in these participants compared to traditional public mental health clients is that nearly all participants had received at least 40 hours of state-approved peer specialist or peer wellness specialist training. State-approved peer-specialist trainings and peer-wellness specialist trainings include advocacy training. Also, nearly all of the participants were working as peer specialists.

Despite these educational advantages, nearly half of the respondents indicated they needed help reading hospital materials occasionally or more frequently. Similarly, nearly two-thirds of the respondents stated that they occasionally or more frequently had difficulty learning about their medical conditions because they had difficulty understanding written material. One can only imagine the challenges that people with psychiatric disabilities have who have less education and advocacy training than the participants have in this study.

Situating Key Findings in Relation to Empirical Research and Theory

Health Literacy Resides in the Relationship, not in the Individual

Health literacy research implies that health literacy is a static, unchanging concept residing in the individual. Nearly every health literacy study (including the author's) measured health literacy once. Measuring health literacy one time may cause one to infer that health literacy is a static concept. There is little commentary, discussion, or explanation in the research as to why researchers measured health literacy once. While one may guess that researchers only measure health literacy once in their studies primarily due to time and cost concerns, I wonder what the impact of measuring health literacy only once is.

Participants in this study discussed situations in which their health literacy may change. Table 9 identifies different situations in which one's health literacy may change for a short period of time or longer. In particular, the table reflects the major findings of this study. This may mean that the study participants usually have the skills and cannot access them on a temporary basis, or it may mean that life has changed, and they need different strategies and knowledge to build their health literacy.

Table 9

Health Literacy Can Be Incredibly Variable

When people are under significant duress

- Having high anxiety
- Experiencing severe depression
- Feeling extreme fear

When people have challenging mental health conditions

- Hearing voices
- Having visions

When the situational environment of people changes

- After a car accident
- After a potentially life-changing diagnosis
- When people live with interpersonal violence

When a major medical diagnosis or health event changes

- Stroke
- Dementia
- Huntington's Disease
- Severe pain
- Covid-19*
- Other diseases or illnesses that impact one's cognitive skills

*I added Covid-19 based on the cognitive challenges and brain fog that people who have had Covid-19 describe. The focus groups and the individual interview occurred prior to the Covid-19 pandemic.

Table 9:Facilitators and Barriers of Health Literacy according to Study Participants

While participants in this study did not identify specific situations in which their health literacy changed, nearly all participants agreed that their health literacy changed when they weren't feeling well. They discussed how much more difficult to complete medical forms when they didn't feel well. Another participant talked about the difficulties of accessing her health literacy skills when she was having extreme anxiety and pre-eclampsia. Still others described the challenges of accessing their health literacy skills when they were having mental health challenges or physical health challenges that compromised their ability to think and evaluate information. Finally, participants identified several health as well as mental health challenges when their healthcare needs were not static but changed over time.

Despite the profusion of health literacy research, the construct of health literacy is still evolving in terms of our understanding (Nutbeam, 2008 and Rudd, 2015), as evidenced by the growing number of definitions of health literacy (Malloy-Weir et al., 2016; Sørensen et al., 2012). The preponderance of health literacy research focuses on health literacy as an individual trait, although there has been some attention paid to addressing the more macro aspects of health literacy (Brega et al., 2019; Farmanova et al., 2018; Khorasani et al., 2020; Logan et al., 2015; McCormack et al., 2017).

This dissertation adds to the body of literature by noting how health literacy is contextual, dynamic, and interactive. Health literacy is a multiply layered construct and does not only reside in the individual but within different levels of a social ecological system (McCormack et al., 2017).

The data from this study suggests that positive relationships with providers may enhance health literacy because people feel more comfortable asking questions to a provider they know and trust. In contrast, people reported more negative experiences that interfered with their health literacy when they encountered healthcare providers who did not know them well, such as in the emergency department or specialty care. These negative experiences inhibited the participants' ability to obtain accurate information about their health conditions and health status and, in some cases, resulted in the delay of needed healthcare and the creation of iatrogenic injury.

The structure of how appointments are scheduled with doctors and other healthcare providers does little to develop positive relationships that enhance health literacy. Patients generally meet with a nurse or a physician's assistant to obtain vital signs and identify the purpose of the visit. People usually have no more than 10-20 minutes with a doctor. It leaves little time for relationship development or for people to process the information their doctor or other healthcare provider gives them. Healthcare systems and payors do not compensate doctors for developing positive patient relationships. Patients have little to no control over how much time they spend with their doctor or what occurs during their appointment. Patients are expected to deliver the essence of an elevator speech to address their health questions and concerns.

People diagnosed with mental health and addiction disorders live every single day managing both their physical health challenges and their mental health/addiction challenges and the interaction between the different challenges. However, medicine and healthcare continue to perpetuate the idea that the conditions and the mind and body are separate. In contract, this study documents that how physical and behavioral health challenges interact and can exacerbate each other when healthcare providers do not view people holistically. Participants in this study described the deficits arising when physical health care providers don't know, understand or address mental health care needs when physical health problems are the primary reason for seeking care. These deficits are not individual traits but are rooted systemically in the mezzo and macro world of healthcare and healthcare systems.

Study Limitations

There are several study limitations. First, recruitment for this study was challenging. The researcher had people who, prior to the beginning of the study, promised to help the researcher recruit participants. However, all but one of the allies were concerned about liability despite the study having Institutional Review Board approval. Hence, this study's sample size is smaller than expected (although it should be noted that focus group-based studies of health literacy or mental health needs are not uncommon.

Second, generalizability was limited due to the specific study context. The participants were from one Northwest state with a specific set of state Medicaid programs and policies. Furthermore, while all participants had used publicly funded physical and mental health services, all but one participant was employed as peer specialists and had a minimum of 40 hours of peer advocacy and system navigation training. Most people who use publicly funded services do not receive peer advocacy training. In addition, participants in this study are highly educated and may differ from many people enrolled in public mental and physical healthcare services. Thus, the data from this study cannot be generalized to traditional users of public mental health services.

Third, there was a technology snafu in the first focus group in which most of the recording was lost. I had two note-takers in that focus group and believe that due to the extensive notetaking, it is believed that little was lost in terms of content. Also, I forgot to assign a unique identifier to participants in order to link what they said in the focus group with their responses in the survey. Therefore, it was not possible to distinguish the data of participants who completed some or all of the survey but did not participate in a focus group versus those who completed the survey and also participated in a focus group.

Finally, there is an analytical limitation that reflects my reliance on narrative. Long narratives are difficult to break into discrete chunks of meaning, and should be used in their entirety (e.g., case studies) to ensure the integrity of the person's story and voice. I used CCA as an analytic tool (Fram, 2013; Glaser & Strauss, 1967). Yet, constant comparative analysis does not lend itself well to analyzing whole narratives. While many qualitative studies focus on one aspect of a person's life, people are complex beings with many factors occurring simultaneously. Many physical and emotional/mental health conditions and substance misuse disorders interact and layer the lived experiences of people with psychiatric disabilities. In short, it was difficult to employ CCA while also supporting a narrative perspective.

Implications for Research and Practice, Programming, and Policies

Implications for Research

This research is very preliminary. Much more research is needed that builds on the lived experiences of people diagnosed with mental health disorders in health literacy and explores the relational nature of health literacy. Similar studies with participants who are more diverse than the participants in this sample are needed especially participants with lower education and lower health literacy.

More research is needed that integrates the lived experiences of people diagnosed with mental illness in community-based settings, residential setting, secure facilities, and state hospitals. These specific settings may have contexts that are unique to the specific type of setting that may be crucial to health literacy in those settings.

Implications for Practice and Programming

There is No Health without Mental Health and No Mental Health without Physical Health

Healthcare providers across all disciplines have operated independently and without integration for hundreds of years in Western society. There is very little integrated healthcare training that treats and acknowledges that the mind and body are one, despite the growing research demonstrating the connection (e.g., coronary care research). Much research is needed to integrate healthcare training for all professions. Research is also needed to make structural improvements that meet patient needs first and payers' needs second such as how doctors' appointments are structured would facilitate health literacy rather than inhibit it.

Additional studies with similar methods that prioritize participants with more diversity than the participants in this study are needed especially participants with lower education and lower health literacy. Studies that focus on people with psychiatric diagnoses who are non-native English speakers are also needed.

What is the role of peer support in supporting health literacy? How do peer specialists support system navigation? Does system navigation look different in organizations where peer support is hired within the organization compared to agencies that contract for peer support services?

Mental health organizations have not generally adopted organizational goals around health literacy. More research is needed to determine best practices for mental health organizations to take up increased health literacy as a goal for the organization.

Policymakers and providers have put much effort into establishing healthcare homes where physical and behavioral healthcare services are integrated. However, according to Murphy et al. (2018), there is little physical health outcomes data, and of what there is, the data is mixed. Furthermore, the implementation of behavioral health homes varies widely (McMurphy et al., 2018). More research is needed that looks at the integration of medical training and the restructuring of the medical encounter process to facilitates health literacy.

In this study, I have demonstrated how the facilitators of and barriers to health literacy are connected to health literacy. Figure 8 shows how the C/S/X community and health literacy intersect and are a part of healthcare quality.

Figure 8

Consumers/Survivors/Ex-patients and Health Literacy in Healthcare Quality

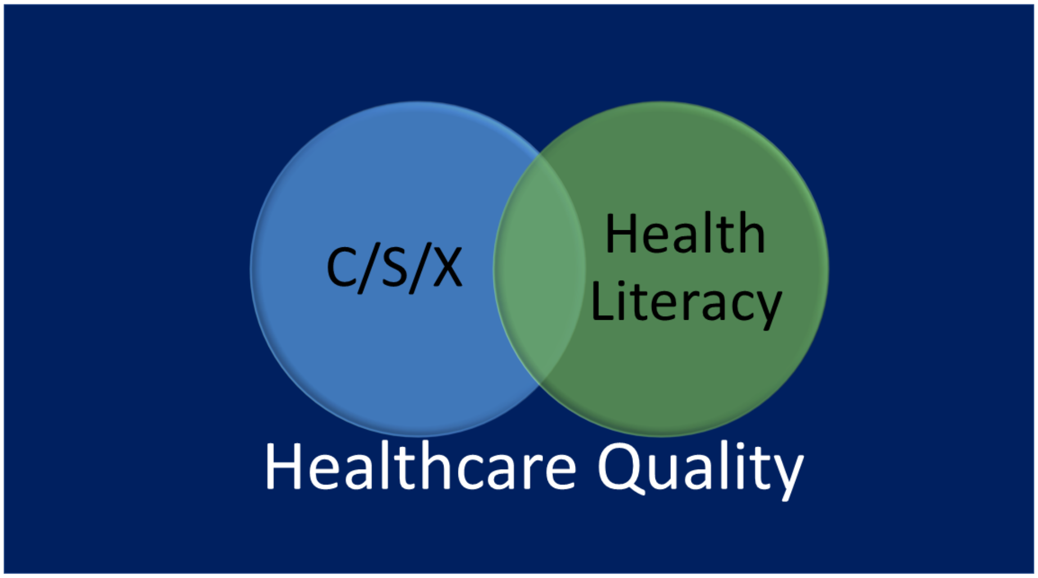

Figure 8: Consumers/Survivors/Ex-patients and Health Literacy in Healthcare Quality

I have not isolated people with psychiatric diagnoses health conditions from their physical health conditions. This is intentional and is a crucial finding of this study.

Health Literacy is Dynamic, not a Point-in-Time Issue

As social workers, we must meet people where they are, including their health literacy level, and consider the person in environment. However, our clients are not required to stay where we met them. Even with small inputs, one can have tremendous change. The "Do as I Say" healthcare model does not result in good outcomes for the person. Giving people a voice and choice results in better outcomes and motivates people to change.

This research also requires traditional social work researchers and people with lived experience collaborating and co-producing new knowledges. Social workers and peer support specialists can teach people to self-advocate and ask better questions. Social workers can partner with people with lived experience to develop recovery support centers that focus on health literacy and health and mental health concerns. Like Promotores de Salud, people with lived experience can work as health system navigators, trainers, and advocates to teach advocacy skills and advocate on behalf of people.

There is an enormous need for recovery education that supports an integrated understanding of people living with mental health and substance misuse challenges while addressing their physical health needs. The integration efforts in healthcare, thus far, are woefully inadequate when we think about the lifespan disparity that people with psychiatric disabilities face. As a result of previous integration efforts, behavioral health providers share offices with primary care practitioners, and public mental health clinics invite primary care practitioners to share space in their clinics. However, the outcomes thus far are unclear. The lifespan disparity between people diagnosed with mental illness and their counterparts who are not diagnosed remains. It is not yet clear what healthcare providers, healthcare systems, and policymakers have done to decrease this disparity.

Lessening the lifespan disparity requires that we rethink what integration means regarding how healthcare providers practice healthcare in all fields. Furthermore, social workers must address the stigmatizing practices, behaviors, and attitudes they hold in order to reduce the devastating and at times life-threatening effects of diagnostic overshadowing and stigma.

When reviewing the health literacy literature, I found few articles authored or co-authored by social workers or social work researchers. Nevertheless, the adjacent field of health promotion had many more social workers authoring or co-authoring papers. More social workers and social work researchers need to share leadership with people with lived experiences of mental health disorders and substance misuse disorders in co-producing knowledge (including by co-authoring papers addressing the health literacy needs of people with psychiatric disabilities.

If we want to improve the health literacy and wellness of people with psychiatric disabilities, social work leaders and social work researchers must re-examine how they work with and support people and social workers with lived experience of psychiatric disabilities. As a profession, social work is behind in the co-production and co-creation of knowledge and policy. There are people with lived experience in the U.S. who are developing programs based on people's lived experiences, such as Pat Deegan's Common Ground program (Deegan, 2005, 2007, 2020a, 2020b; Deegan & Drake, 2006; Drake et al., 2010) and the United Kingdom's Service Users' Research Enterprise (Keetharuth et al., 2018; Pallesen et al., 2020; Rose et al., 2017; Rose & Kalathil, 2019; Sweeney et al., 2018; Williams et al., 2020). Social work leaders can listen more deeply to people with lived experience and co-develop trauma-informed and culturally responsive programs that advocate for people with psychiatric disabilities and educate other healthcare providers.

Participants in this study discussed how self-advocacy is not without risks and potential negative consequences. These risks may create iatrogenic harm, such as the denial of appropriate medical care and coercion, which could end up with life-altering consequences and the potential loss of freedom (through civil commitment). When people with psychiatric disabilities self-advocate individually, there is a greater risk than when people advocate together as part of a group. Social workers can partner with people with lived experience to create coalitions and groups that advocate for better care. The advocacy objective should be to develop and implement practices and programs that enhance the health literacy of people with lived experience and reduces their risk of negative consequences associated with self-advocacy. However, medical self-advocacy fails to address the structural problems of healthcare professions' lack of integrated training or the problematic structures of the medical encounter.

Previous efforts to develop more person-centered practices in medicine, such as narrative medicine (Charon, 2001, 2011; Charon et al., 2008; Mezzich et al., 2010), have been undertaken. The impact of person-centered practices is hard to see when it comes to improving the health literacy of people with psychiatric disabilities. Healthcare seems to have retreated from person-centered medicine and retrenched itself in regular care. The purpose of this dissertation is not to critique medicine but to advance what social work can do to improve health literacy and healthcare overall.

Holistic integration must include trauma-informed care, and cultural humility, as well as perspectives that attend to diverse people's cultures, and that respect their ways of knowing and understanding the world. Despite numerous efforts to reduce disparities in healthcare, the people of color in this study described stark differences in their health literacy when they received culturally specific and responsive care.

The building blocks of potential programs currently exist in terms of the development of peer specialists, family peer specialists, recovery mentors, peer-wellness specialists, and personal medicine coaches who are trained to support people with lived experience in terms of health literacy and advocacy. These programs must be more available to all people with psychiatric disabilities and have standards and practices that truly support people with lived mental health and substance misuse services and reflect the authentic values of peer support.

Supervision standards that support peer support workers' values and knowledge base must be established. Frequently, social workers supervise support workers. Although social works and peer support workers share many values, the differences need to be respected. For example, social workers are usually trained to not share aspects of their personal experience with their clients. Peer support workers (regardless of type of peer specialist) believe in using their personal experience through strategic sharing. I have had conversations with many peer specialists who are discouraged from sharing their personal experience with the people they support.

Social workers who supervise peer specialists should understand and acknowledge those differences to support the peer support workers they supervise. Social workers who supervise peer support workers also should acknowledge and honor the differences in the values and knowledge base.

Finally, there is a great need for more narrative and multi-media research that allows people with psychiatric disabilities to be the storyteller of record. They need a chance to be the author of their own narrative that is not subjected to the whims of a healthcare system that says they are valued and then disregards them. Perhaps people with psychiatric diagnoses will find ways to build their health literacy skills through such research.

Policy Recommendations

All policy change work should be done in solidarity with people who use or have used mental health and addiction services. Development is needed for policies that support multidisciplinary teamwork and the inclusion of people with lived experiences as equitable partners. These policies must also address the continuing education needs of peer specialists. Additional policies that need development would support self-advocacy and reduce the risk of iatrogenic harm to people who self-advocate. Developing policies that support self-advocacy may require collaboration with other healthcare professionals to review and replace current policies and practices. Policies also need to be developed that support trauma-informed care and personalized recovery as well as healthcare education that supports integrative and culturally specific needs of people with psychiatric and substance misuse diagnoses.

Conclusion

This study aimed to identify the health literacy needs of people diagnosed with mental illness. Surprisingly, the critical finding stands out in contrast to most health literacy literature. Health literacy is a complex construct that is dynamic and relationship-based. Social work is well-positioned to collaborate and partner with people in building this new knowledge because of our person-in-environment perspective.

This study creates new knowledge and understanding of health literacy. A clear implication is that much work is needed to understand the dynamic interaction of health literacy further. To quote Jasna Russo (Russo, 2022), an activist and researcher with lived experience, social work must not "be afraid to open up complexities – we do not expect answers and solutions, but seek to advance our thinking and offer agendas for action on many different levels" (p. 363).

References

Albino, S., Tabb, K. M., Requena, D., Egoavail, M., Pineros-Leano, M. F., Zunt, J. R., & Garcia, P. J. (2014). Perceptions and acceptability of short message services technology to improve treatment adherence amongst tuberculosis patients in Peru: a focus group study. *PLoS One*, *9*(5), e95770. https://doi.org/10.1371/journal.pone.0095770

American Psychiatric Associaion. (2014). *Diagnostic and Statistical Manual V*. American Psychiatric Publishing, Inc.

Andersen, R. M. (1995). Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behavior*, *36*(1), 1. https://doi.org/10.2307/2137284

Andersen, R. M., & Newman, J. F. (1973). Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund Quarterly. Health and Society*, *51*(1), 95–124. https://doi.org/10.2307/3349613

Ayalon, L., & Alvidrez, J. (2007). The experience of black consumers in the mental health system - Identifying barriers to and facilitators of mental health treatment using the consumers’ perspective. *Issues in Mental Health Nursing*, *28*(12), 1323–1340. https://doi.org/10.1080/01612840701651454

Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, *21*(8), 878–883. https://doi.org/10.1111/j.1525-1497.2006.00540.x

Baker, D. W., Gazmararian, J. A., Williams, M. V, Scott, T. L., Parker, R. M., Green, D., Ren, J., & Peel, J. (2002). Health literacy and use of outpatient physician services by Medicare managed care enrollees. *Medical Care*, *40*(5), 395–404.

Baker, D. W., Parker, R. M., Williams, M. V, & Clark, W. S. (1998). Health literacy and the risk of hospital admission. *Journal of Generall Internal Medicine*, *13*(12), 791–798.

Baker, D. W., Parker, R. M., Williams, M. V, Clark, W. S., & Nurss, J. R. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health*, *87*(6), 1027–1030.

Baker, D. W., Parker, R. M., Williams, M. V, Pitkin, K., Parikh, N. S., Coates, W., Imara, M., & Med, F. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine*, *5*(6), 329–334.

Baker, D. W., Williams, M. V, Parker, R. M., Gazmararian, J. A., & Nurss, J. R. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, *38*(1), 33–42.

Balsa, A. I., & Mcguire, T. G. (2003). Prejudice, clinical uncertainty and stereotyping as sources of health disparities. *Journal of Health Economics*, *22*(1), 89–116.

Barefoot, J. C., Helms, M. J., Mark, D. B., Blumenthal, J. A., Califf, R. M., Haney, T. L., O'Connor, C. M., Siegler, I. C., & Williams, R. B. (1996). Depression and long-term mortality risk in patients with coronary artery disease. *American Journal of Cardiology*, *78*, 613–617.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability: A sociological introduction*. Blackwell.

Barton, L. (Ed.). (1996). *Disability & society: Emerging issues and insights*. Longman.

Barton, L. (1998). Sociology, disability studies and education: Some observations. In T. Shakespeare (Ed.), *The Disability Reader: Social science perspectives* (pp. 53–64). Bloomsbury Academic.

Bass III, P. F., Wilson, J. F., & Griffith, C. H. (2003). A shortened instrument for literacy screening. *Journal of General Internal Medicine*, *18*, 1036–1038. https://doi.org/10.1111/j.1525-1497.2003.10651.x

Bassman, R. (2001). Whose reality is it anyway? Consumers/survivors/ex-patients can speak for themselves. *Journal of Humanistic Psychology*, *41*(4), 11–35.

Becker, S., Sempik, J., & Bryman, A. (2010). Advocates, Agnostics and Adversaries: Researchers' Perceptions of Service User Involvement in Social Policy Research. *Social Policy and Society*, *9*(03), 355–366. https://doi.org/10.1017/S1474746410000072

Beers, C. (1923). *A Mind That Found Itself*. Doubleday.

Beresford, P. (2000a). What Have Madness and Psychiatric System Survivors Got to Do with Disability and Disability Studies? *Disability & Society*, *15*(1), 167–172. https://doi.org/10.1080/09687590025838

Beresford, P. (2000b). Service users' knowledges and social work theory: conflict or collaboration? *British Journal of Social Work*, *30*(4), 489–503. https://doi.org/10.1093/bjsw/30.4.489

Beresford, P. (2002). User involvement in research and evaluation--Liberation or regulation. *Social Policy & Society*, *1*(2), 95–105.

Beresford, P. (2003a). *It's Our Lives: A short theory of knowledge, distance and experience*. Citizen Press; Shaping Our Lives. https://www.shapingourlives.org.uk/documents/ItsOurLives.pdf

Beresford, P. (2003b). *It's Our Lives: A short theory of knowledge, distance and experience*. Shaping Our Lives.

Beresford, P. (2005a). Social approaches to madness and distress: User perspectives and user knowledge. In J. Tew (Ed.), *Social Perspectives in Mental Health* (pp. 32–52). Jessica Kingsley Publishers.

Beresford, P. (2005b). Social work and a social model of madness and distress : Developing a viable role for the future. *Social Work & Social Sciences Review*, *12*(2), 59–73.

Beresford, P. (2007). User involvement, research and health inequalities: Developing new directions. *Health and Social Care in the Community*, *15*(4), 306–312. https://doi.org/10.1111/j.1365-2524.2007.00688.x

Beresford, P., & Evans, C. (1999). Research note: Research and Empowerment. *British Journal of Social Work*, *29*, 671–677.

Beresford, P., Gifford, G., & Harrison, C. (1996). What does disability got to do with psychiatric survivors. In J. Read & J. Reynolds (Eds.), *Speaking our minds: An anthology* (pp. 209–214). MacMillan.

Beresford, P., & Rose, D. (2009). Introduction. In A. Sweeney, P. Beresford, A. Faulkner, M. Nettle, & D. Rose (Eds.), *This Is Survivor Research*. PCCS Books.

Berg, A., & Hammitt, K. B. (1980). Assessing the psychiatric patient's ability to meet the literacy demands of hospitalization. *Hospital & Community Psychiatry*, *31*(4), 266–268.

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. Doubleday.

Berkman, N. D., Davis, T. C., & McCormack, L. (2010). Health literacy: what is it? *Journal of Health Communication*, *15 Suppl 2*, 9–19. https://doi.org/10.1080/10810730.2010.499985

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: care, health, and cost. *Health Affairs (Project Hope)*, *27*(3), 759–769. https://doi.org/10.1377/hlthaff.27.3.759

Bogart, L. M., Fremont, A. M., Young, A. S., Pantoj, P., Chinman, M., Morton, S., Koegel, P., Sullivan, G., & Kanouse, D. E. (2006). Patterns of HIV care for patients with serious mental illness. *AIDS Patient Care and STDs*, *20*(3), 175–183.

Boyle, M. (1999). Diagnosis. In C. Newness, G. Holmes, & C. Dunn (Eds.), *This is madness: A critical look at psychiatry and the future of mental health services* (pp. 75–90). PCCS Books.

Brach, C., Dreyer, B., Schyve, P., Hernandez, L. M., Baur, C., Lemerise, A. J., & Parker, R. (2012). *Attributes of a Health Literate Organization* (Issue January).

Braye, S. (2000). Participation and involvement in social care: An overview. In H. Kemshall & R. Littlechild (Eds.), *User involvement and Participation in Social Care: Research informing Practice*. Jessica Kingsley Publishers.

Brisenden, S. (1998). Independent living and the medical model of disability. In T. Shakespeare (Ed.), *The Disability Reader: Social science perspectives* (pp. 20–27). Cassell.

Buchbinder, R., Batterham, R., Elsworth, G., Dionne, C. E., Irvin, E., & Osborne, R. H. (2011). A validity-driven approach to the understanding of the personal and societal burden of low back pain: development of a conceptual and measurement model. *Arthritis Research & Therapy*, *13*(5), R152. https://doi.org/10.1186/ar3468

Calvo, R. (2014). Health Literacy and Quality of Care among Latino Immigrants in the United States. *Health and Social Work*, *41*(1), e44–e51. https://doi.org/10.1093/hsw/hlv076

Campbell, J. E. (2009). Methods: “We are the evidence,” an examination of service user reseearch involvement as voice. In J. Wallcraft, B. Schrank, & M. Amering (Eds.), *Handbook of Service User Involvement in Mental Health Research* (pp. 113–138). Wiley-Blackwell.

Campbell, J., & Oliver, M. A. (1996). *Disability politics: Understanding our past: changing our future.* Routledge.

Campbell, J., & Schraiber, R. (1989). *In purusit of wellness*.

Caplan, P. J. (2004a). *Bias in psychiatric diagnosis*. Jason Aronson, Inc.

Caplan, P. J. (2004b). *Bias in psychiatric diagnosis*. Jason Aronson, Inc.

Chamberlin, J. (1979). *On Our Own: Patient controlled alternatives to the mental health system*. National Empowerment Center.

Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we're going. *Journal of Mind and Behavior*, *11*(3/4), 323–336. https://doi.org/10.5437/08956308X5504085

Chamberlin, J. (2005). User/consumer involvement in mental health service delivery. *Epidemiologia e Psichiatria Sociale*, *14*(1), 10–14. https://doi.org/10.1017/S1121189X00001871

Chamberlin, J., Rogers, E. S., & Ellison, M. L. (1996). Self-Help Programs: A Description of Their Characteristics and Their Members. *Psychiatric Rehabilitation Journal*, *19*(3), 33–42.

Charlton, J. I. (1998). *Nothing about us without us.* University of California Press.

Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine*, *36*(8), 588–594. https://doi.org/10.1186/1471-2458-12-80

Chew, L. D., Griffin, J. M., Partin, M. R., Noorbaloochi, S., Grill, J. P., Snyder, A., Bradley, K. a, Nugent, S. M., Baines, A. D., & Vanryn, M. (2008). Validation of screening questions for limited health literacy in a large VA outpatient population. *Journal of General Internal Medicine*, *23*(5), 561–566. https://doi.org/10.1007/s11606-008-0520-5

Chinn, D. (2011). Critical health literacy: a review and critical analysis. *Social Science & Medicine (1982)*, *73*(1), 60–67. https://doi.org/10.1016/j.socscimed.2011.04.004

Christensen, R. C., & Grace, G. D. (1999). The prevalence of low literacy in an indigent psychiatric population. *Psychiatric Services*, *50*(2), 262–263.

Circulation. (1995). Depression and 18-month prognosis after myocardial infarction. *Frasure-Smith, N. Lesperance, F. Talajic, M.*, *91*, 999–1005.

Clarke, D. E., Dusome, D., & Hughes, L. (2007). Emergency department from the mental health client's perspective: Feature article. *International Journal of Mental Health Nursing*, *16*, 126–131. https://doi.org/10.1111/j.1447-0349.2007.00455.x

Claro, R. M., Linders, H., Ricardo, C. Z., Legetic, B., & Campbell, N. R. C. (2012). Consumer attitudes, knowledge, and behavior related to salt consumption in sentinel countries of the Americas. *Pan American Journal of Public Health*, *32*(4), 265–273. https://doi.org/10.1590/S1020-49892012001000004

Clausen, W., Watanabe-Galloway, S., Baerentzen, B. M., & Britigan, D. H. (2016). Health Literacy Among People with Serious Mental Illness. *Community Mental Health Journal*, *52*(4), 399–405. https://doi.org/10.1007/s10597-015-9951-8

Coles, G. S., Roth, L., & Pollack, I. W. (1978). Literacy skills of long-term hospitalized mental patients. *Hospital & Community Psychiatry*, *29*(8), 512–516.

Colombo, A., Bendelow, G., Fulford, B., & Williams, S. (2003). Evaluating the influence of implicit models of mental disorder on processes of shared decision making within community-based multi-disciplinary teams. *Social Science & Medicine (1982)*, *56*(7), 1557–1570.

Consumer Quality Initiative. (2007). *Consumer Quality Initiative: CQI History*. http://www.cqi-mass.org/hisotry.aspx.

Coppick, V., & Hopton, J. (2000). *Critical perspectives on mental health*. Tavistock.

Corrigan, P., & Watson, A. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*(1), 16–20.

Corrigan, P. W. ., Salzer, M., Ralph, R. O., Sangster, Y., & Keck, L. (2004). Examining the factor structure of the recovery assessment scale. *Schizophrenia Bulletin*, *30*(4), 1035–1041.

Crewe, N. M., & Harkins, A. (1983). *Independent living for physically disabled people* (N. Crewe & K. Z. and A. Irving, Eds.). Jossey-Bass.

Culhane-Pera, K. a, Moua, M., DeFor, T. a, & Desai, J. (2009). Cardiovascular disease risks in Hmong refugees from Wat Tham Krabok, Thailand. *Journal of Immigrant and Minority Health*, *11*(5), 372–379. https://doi.org/10.1007/s10903-008-9211-x

Currier, G. W., Sitzman, R., & Trenton, A. (2001). Literacy in the psychiatric emergency service. *The Journal of Nervous and Mental Disease*, *180*(1), 56–58.

Dastjerdi, M. (2012). The case of Iranian immigrants in the greater Toronto area: a qualitative study. *International Journal of Equity and Health*, *11*(9). https://doi.org/10.1186/1475-9276-11-9

Davis, T. C., Long, S. W., Jackson, R. H., Mayeaux, E. J., George, R. B., Murphy, P. W. ;, & Crouch, M. A. (1993). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*, *25*, 391–395.

Davis, T. C., Mayeaux, E. J., Fredrickson, D., Bocchini, Jr., J. A., Jackson, R. H., & Murphy, P. W. (1994). *Reading ability of parents compared with reading ability of pediatric patient education materials.* 450–468.

Deegan, P. E. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, *9*(4), 11–19.

Deegan, P. E. (1992). The Independent Living Movement and people with psychiatric disabilities: Taking back control over our own lives. *Psychosocial Rehabilitation Journal*, *15*(3), 3–19. https://doi.org/10.1037/h0095769

Deegan, P. E. (1996). *Reclaiming your power during medication appointments with your psychiatrist - NEC Article*. http://www.power2u.org/articles/selfhelp/reclaim.html

Deegan, P. E. (2000). Spirit breaking: When the helping professions hurt. *The Humanistic Psychologist*, *28*(1–3), 194–209. https://doi.org/10.1080/08873267.2000.9976991

Deegan, P. E. (2010). A web application to support recovery and shared decision making in psychiatric medication clinics. *Psychiatric Rehabilitation Journal*, *34*(1), 23–28. https://doi.org/10.2975/34.1.2010.23.28

Degan, T. J., Kelly, P. J., Robinson, L. D., Deane, F. P., & Smith, A. M. (2021). Health literacy of people living with mental illness or substance use disorders: A systematic review. In *Early Intervention in Psychiatry* (Vol. 15, Issue 6, pp. 1454–1469). John Wiley and Sons Inc. https://doi.org/10.1111/eip.13090

Degan, T. J., Kelly, P. J., Robinson, L. D., Deane, F. P., Wolstencroft, K., Turut, S., & Meldrum, R. (2019). Health literacy in people living with mental illness: A latent profile analysis. *Psychiatry Research*, *280*. https://doi.org/10.1016/j.psychres.2019.112499

Demian, M. N., Jean Shapiro, R., & Thornton, W. L. (2016). An observational study of health literacy and medication adherence in adult kidney transplant recipients. *Clinical Kidney Journal*, *9*(6), 858–865. https://doi.org/10.1093/ckj/sfw076

Democracy Disability and Society Group. (2003). *Medical Model of Disability*. http://ddsg.org.uk/taxi/medical-model.html

Desai, M. M., Rosenheck, R. A., Druss, B. G., & Perlin, J. B. (2002). Mental disorders and quality of diabetes care in the Veterans Health Administration. *American Journal of Psychiatry*, *159*(September), 1584–1590.

DeWalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes: A systematic review of the literature. *Evidence Report/Technology Assessment (Summary)*, *19*(12), 1228–1239.

Dickson, V. V., Lee, C. S., & Riegel, B. (2011). How do cognitive function and knowledge affect heart failure self-care? *Journal of Mixed Methods Research*, *5*(2), 167–189.

Dixon, L., Weiden, P., Delahanty, J., Qoldberg, R., Postrado, L., Lucksted, A., & Lehman, A. (2000). Prevalence and correlates of diabetes in national schizophrenia samples. *Schizophrenia Bulletin*, *26*(4), 903–912.

Dray, S., & Papen, U. (2004). Literacy and health: towards a methodology for investigating patients' participation in healthcare. *Journal of Applied Linguistics*, *1*(3), 311–332.

Eichler, K., Wieser, S., & Brügger, U. (2009). The costs of limited health literacy: a systematic review. *International Journal of Public Health*, *54*(5), 313–324. https://doi.org/10.1007/s00038-009-0058-2

Executive Order 12866. (1993). Federal Register.

Executive Order 12988 (pp. 4727–4734). (1996). Federal Register.

Executive Order 13563 (Vol. 76, Issue 14). (2011). Federal Register.

Fadiman, A. (1997). *The Spirit Catches You and Then You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*. Farrar, Straus and Giroux.

Fairclough, N. (1992). *Discourse and social change*. Polity Press.

Farrell, S. J., Dunn, M., & Huff, J. (2020). Examining Health Literacy Levels in Homeless Persons and Vulnerably Housed Persons with Mental Health Disorders. *Community Mental Health Journal*, *56*(4), 645–651. https://doi.org/10.1007/s10597-019-00525-2

Faulkner, A. (2009). Principles and motives for service user involvement in mental health research. In J. Wallcraft, B. Schrank, & M. Amering (Eds.), *Handbook of Service User Involvement in Mental Health Research2*. Wiley-Blackwell.

Felker, B., Yazel, J. J., & Short, D. (1996). Mortality and Medical Comorbidity Among Patients With Serious Mental Illness. *Psychiatric Services*, *47*(12), 1356–1363.

Fetter, M. S. (2009). Promoting health literacy with vulnerable behavioral health clients. *Issues in Mental Health Nursing*, *30*(12), 798–802. https://doi.org/10.3109/01612840902887725

Findlay, A. (2015). Social Work in Health Care Low Health Literacy and Older Adults: Meanings, Problems, and Recommendations for Social Work. *Social Work in Health Care*, *54*(1), 65–81. https://doi.org/10.1080/00981389.2014.966882

Findley, A. (2015a). Low health literacy and older adults: meanings, problems, and recommendations for social work. *Social Work in Health Care*, *54*(1), 65–81. https://doi.org/10.1080/00981389.2014.966882

Findley, A. (2015b). Low Health Literacy and Older Adults: Meanings, Problems, and Recommendations for Social Work. *Social Work in Health Care*, *54*(1), 65–81. https://doi.org/10.1080/00981389.2014.966882

Fisher, D. B., & Ahern, L. (2002). Evidence-Based Practices and Recovery. *Psychiatric Services*, *53*(5), 632-a-633. https://doi.org/10.1176/appi.ps.53.5.632-a

Flaskerud, J. H. (2012). Mental health care and health literacy. *Issues in Mental Health Nursing*, *33*, 196–198.

Fleischmann, P. (2009). Literature Reviews: An example of making traditional research methods user focused. In A. Sweeney, P. Beresford, A. Faulkner, M. Nettle, & D. Rose (Eds.), *This Is Survivor Research* (pp. 82–97). PCCS Books.

Fleishmann, P. (2009). Literature reviews: An example of making tradtional research methods user focused. In A. Sweeney, P. Beresford, A. Faulkner, M. Nettle, & D. Rose (Eds.), *This Is Survivor Research* (pp. 82–97). PCCS Books.

Fram, S. M. (2013). The Constant Comparative Analysis Method Outside of Grounded Theory. In *The Qualitative Report* (Vol. 18, Issue 1). http://www.nova.edu/ssss/QR/QR18/fram1.pdf

Frank, L. R. (1978). *The history of shock treatment*. Leonard Roy Frank.

Friedland, R. (1998). New estimates of the high costs of inadequate health literacy. *Proceedings of Pfizer Conference "Promoting Health Literacy: A Call to Action.*, 6–10.

Friere, P. (1970). *Pedagogy of the Oppressed* (30th Anniv). Continuum.

Fulford, B. (KWM). (1989). *Moral theory and medical practice*. Cambride University Press.

Fulford, B. (KWM), & Wallcraft, J. (2009). Values-based Practice and Service User Involvement in Mental Health Research. In J. Wallcraft, B. Schrank, & M. Amering (Eds.), *Handbook of Service User Involvement in Mental Health Research* (pp. 37–60). John Wiley & Sons.

Gabel, S. (1999). Depressed and disabled: Some discursive problems with mental illness. In M. Corker & S. French (Eds.), *Disability Discourse* (pp. 38–46). Routledge.

Galletty, C. A., Lincoln, A. K., & Arford, T. (2013). Health literacy and people with mental illness. In R. Moore & D. Perry (Eds.), *Health literacy: developments, issues and outcomes* (pp. 143–158). Nova Science Publishers.

Garey, J. (2013, August 10). When doctors discriminate. *The New York Times*.

Gazmararian, J. A., Baker, D. W., Parker, R. M., & Blazer, D. G. (2000). A Multivariate Analysis of Factors Associated With Depression. *Archives of Internal Medicine*, *160*, 3307–3314.

Glaser, B. G. (1965). The Constant Comparative Method of Qualitative Analysis. *Social Problems*, *12*(4), 436–445.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine De Gruyter.

Glassman, P., & Almader-Douglas, D. (2013). *Health Literacy*. http://nnlm.gov/outreach/consumer/hlthlit.html

Goffman, E. (1965). *Stigma; Notes on the management of spoiled identity.* Prentice Hall.

Gordon, M.-M., Hampson, R., Capell, H. a, & Madhok, R. (2002). Illiteracy in rheumatoid arthritis patients as determined by the Rapid Estimate of Adult Literacy in Medicine (REALM) score. *Rheumatology*, *41*(7), 750–754.

Greenberg, D. (2001). A critical look at health literacy. *Adult Basic Education*, *11*(2), 67–79.

Groce, N. E. (1985). *Everyone here spoke sign language: Hereditar deafness on Martha's Vineyard*. Harvard University.

Hall, J. (2013, October 18). Mental illness: is "chemical imbalance" theory a myth? *The Star*.

Hall, R. C. W., Gardner, E. R., Popkin, M. A., Lecann, A. F., & Stickney, S. K. (1981). Unrecognized physical illness prompting psychiatric admission: A prospective study. *American Journal of Psychiatry*, *138*(5), 629–635.

Hall, R. C. W., Gardner, E. R., & Popkin, M. K. (1982). The Medical Care of Psychiatric Patients. *Hospital & Community Pscyhiatry*, *33*(1), 25–34.

Hannawa, A. F., Wu, A. W., Kolyada, A., Potemkina, A., & Donaldson, L. J. (2021). The aspects of healthcare quality that are important to health professionals and patients:

A qualitative study. *Patient Education and Counseling*. https://doi.org/10.1016/j.pec.2021.10.016

Happell, B., Scott, D., & Platania-Phung, C. (2012). Perceptions of barriers to physical health care for people with serious mental illness: a review of the international literature. *Issues in Mental Health Nursing*, *33*(11), 752–761. https://doi.org/10.3109/01612840.2012.708099

Harangozo, J., Reneses, B., Brohan, E., Sebes, J., Csukly, G., López-Ibor, J., Sartorius, N., Rose, D., & Thornicroft, G. (2013). Stigma and discrimination against people with schizophrenia related to medical services. *The International Journal of Social Psychiatry*, *60*(4), 359–366. https://doi.org/10.1177/0020764013490263

Hardie, N. a, Kyanko, K., Busch, S., Losasso, A. T., & Levin, R. a. (2011). Health literacy and health care spending and utilization in a consumer-driven health plan. *Journal of Health Communication*, *16 Suppl 3*(January 2015), 308–321. https://doi.org/10.1080/10810730.2011.604703

Hare, R. M. (1952). *The language of morals*. Oxford University Press.

Haun, J. N., Valerio, M. a, McCormack, L. a, Sørensen, K., & Paasche-Orlow, M. K. (2014). Health literacy measurement: an inventory and descriptive summary of 51 instruments. *Journal of Health Communication*, *19 Suppl 2*(April 2015), 302–333. https://doi.org/10.1080/10810730.2014.936571

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science and Medicine*, *292*. https://doi.org/10.1016/j.socscimed.2021.114523

(HHS), U. S. D. of H. & H. S. (2000). *Healthy People 2010*.

Hill, L. H. (2004). Health literacy is a social justice issue that affects us all. *Adult Learning*, *15*(1/2), 4–6.

Howard, D. H., Gazmararian, J. A., & Parker, R. M. (2005). The impact of health literacy on the medical costs of Medicare managed care enrollees. *The American Journal of Medicine*, *1118*, 371–377.

Institute of Medicine. (2004). *Health literacy: A prescription to end confusion*. Institute of Medicine.

James, D. J., & Glaze, L. E. (2006). Mental Health Problems of Prison and Jail Inmates. In *Bureau of Justice Statistics Special Report*.

John Wiley & Sons, Inc. (2014). *EBM: Levels of Evidence - Essential Evidence Plus*. http://www.essentialevidenceplus.com/product/ebm_loe.cfm?show=oxford

Jones, S., Howard, L., & Thornicroft, G. (2008). “Diagnostic overshadowing”: Worse physical health care for people with mental illness. In *Acta Psychiatrica Scandinavica* (Vol. 118, Issue 3, pp. 169–171). https://doi.org/10.1111/j.1600-0447.2008.01211.x

Jones, S., Howard, L., & Thronicroft, G. (2008). “Diagnostic overshadowing”: worse physical health care for people with mental illness. *Acta Psychiatrica Scandinavica*, *118*, 169–171. https://doi.org/10.1111/j.1600-0447.2008.01211.x

Jordan, J. E., Buchbinder, R., & Osborne, R. H. (2010). Conceptualising health literacy from the patient perspective. *Patient Eucation and Counseling*, *79*(1), 36–42. https://doi.org/10.1016/j.pec.2009.10.001

Jordan, J. E., Osborne, R. H., & Buchbinder, R. (2011). Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *Journal of Clinical Epidemiology*, *64*(4), 366–379. https://doi.org/10.1016/j.jclinepi.2010.04.005

Jorm, A. F., Korten, A. E., Jacomb, P. A., Christensen, H., Rodgers, B., & Pollitt, P. (1997). Mental health literacy: a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment beliefs about the effectiveness of treatment. *Medical Journal of Australia*, *166*(82), 182–186.

Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. In *Patient Education and Counseling* (Vol. 94, Issue 3, pp. 291–309). https://doi.org/10.1016/j.pec.2013.10.031

Kaestle, K. F., Moore, H. D., Stedman, L. C., & Tinsley, K. (1991). *Literacy in the United States : readers and reading since 1880*. Yale University Press.

Kalathil, J. (2011). *Recovery and resilience: African, African-Carribean and South Asian women's narratives of recovering from mental distress*. Mental Health Foundation.

Kalichman, S. C., Benotsch, E., Suarez, T., Catz, S., Miller, J., & Rompa, D. (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine*, *18*(4), 325–331.

Kalichman, S. C., Cain, D., Fuhrel, A., Eaton, L., Di Fonzo, K., & Ertl, T. (2005). Assessing medication adherence self-efficacy among low-literacy patients:

development of a pictographic visual analogue scale. *Health Education Research*, *20*(1), 24–35. https://doi.org/10.1093/her/cyg106

Kalichman, S. C., & Ramachandran, B. B. (2000). Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirolog*, *25*(4), 337–344.

Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine*, *14*(5), 267–273.

Karasu, T. B., Waltzman, S. A., Linedenmayer, J.-P., & Buckley, P. J. (1980). The medical care of patients with psychiatric illness. *Hospital & Community Pscyhiatry*, *11*(7), 463–472.

Kassenbaum, G. G., & Baumann, B. G. (1965). Dimensions of the sick role in chronic illness. *Journal of Health and Human Behavior*, *6*(1), 16–27.

Kaufman, A. S., & Kaufman, J. L. (1990). *Kaufman Brief Intelligence Test*. American Guidance Service.

Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C. B. (1995). Posttraumatic Stress Disorder in the National Co-morbidity Survey. *Archives of General Psychiatry*, *52*, 1048–1060.

Kim, M. T., Hill, M. N., Bone, L. R., & Levine, D. M. (2000). Development and testing of Hill-Bone compliance to high blood pressure therapy scale. *Progress in Cardiovascular Nursing*, *31*, 555–563.

Kirsch, I. S., Jungeblut, A., Jenkins, L., & Kolstad, A. (1993a). *Adult literacy in America: A first look at the findings of the National Adult Literary Survey*.

Kirsch, I. S., Jungeblut, A., Jenkins, L., & Kolstad, A. (1993b). *in America A First Look at the Findings of the National Adult Literacy Survey*.

Klinge, V., & Dorsey, J. (1993). Correlates of the Woodcock-Johnson reading comprehension and Kaufman brief intelligence test in a forensic psychiatric population. *Journal of Clinical Psychology*, *49*(4), 593–598.

Koh, H. K., Baur, C., Brach, C., Harris, L. M., & Rowden, J. N. (2013). Toward a systems approach to health literacy research. *Journal of Health Communication*, *18*(1), 1–5. https://doi.org/10.1080/10810730.2013.759029

Koranyi, E. K. (1979). Morbidity and rate of undiagnosed physical illnesses in a psychiatric clinic opulation. *Archives of General Psychiatry*, *36*, 414–419.

Krishan, S., von Esenwein, S. a, & Druss, B. G. (2012a). The health literacy of adults with severe mental illness. *Psychiatric Services*, *63*(4), 397. https://doi.org/10.1176/appi.ps.20120p397

Krishan, S., von Esenwein, S. a, & Druss, B. G. (2012b). The health literacy of adults with severe mental illness. *Psychiatric Services*, *63*(4), 397. https://doi.org/10.1176/appi.ps.20120p397

Kutchins, H., & Kirk, S. (1999). *Making us crazy: DSM--The Psychiatric Bible and the creation of mental disorders*. McGraw-Hill.

Kutner, M., Greenberg, E., Jin, Y., Boyle, B., Hsu, Y., Dunleavy, E., & White, S. (2007). *Literacy in Everyday Life Results From the 2003 National Assessment*.

Kutner, M., Greenberg, E., Ying, J., Paulsen, C., & White, S. (2006). *The Health Literacy of America's Adults Results From the 2003 National Assessment*.

Laing, R. D. (1965). *The divided self*. Pelican.

Legacy Health. (2014). Making meaning. In *2014 Health Literacy Conference Brochure*. Legacy Health. https://doi.org/10.1136/pgmj.2008.075523

Levinson Miller, C., Druss, B. G., Dombrowski, E. A., & Rosenheck, R. A. (2003). Barriers to primary medical care among patients at a community mental health center. *Psychiatric Services*, *32*(1), 54–55. https://doi.org/10.1024/0301-1526.32.1.54

Lewis-Beck, M. S., Bryman, A., & Liao, T. F. (Eds.). (2011). Constant Comparison. In *The SAGE Encyclopedia of Social Science Research Methods* (p. 181). SAGE Publications, Inc.

Liechty, J. M. (2011). Health literacy: critical opportunities for social work leadership in health care and research. *Health & Social Work*, *36*(2), 99–107.

Lincoln, A. K., Arford, T., Prener, C., Garverich, S., & Koenen, K. C. (2013). The need for trauma-sensitive language use in literacy and health literacy screening instruments. *Journal of Health Communication*, *18 Suppl 1*(June 2014), 15–19. https://doi.org/10.1080/10810730.2013.825676

Lincoln, A. K., Espejo, D., Johnson, P., Paasche-Orlow, M. K., Speckman, J. L., Webber, T. L., & White, R. F. (2008). Limited literacy and psychiatric disorders among users of an urban safety-net hospital's mental health outpatient clinic. *The Journal of Nervous and Mental Disease*, *196*(8), 687–693.

Lincoln, A. K., Paasche-Orlow, M. K., Cheng, D. M., Lloyd-Travaglini, C., Caruso, C., Saitz, R., & Samet, J. H. (2006). Impact of health literacy on depressive symptoms and mental health-related: quality of life among adults with addiction. *Journal of General Internal Medicine*, *21*(8), 818–822. https://doi.org/10.1111/j.1525-1497.2006.00533.x

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications, Inc.

Lived Experience Research Network (LERN). (2013). *User/Survivor Leadership & Capacity Building in Research*.

Ljungberg, A., Denhov, A., & Topor, A. (2015). The Art of Helpful Relationships with Professionals: A Meta-ethnography of the Perspective of Persons with Severe Mental Illness. *Psychiatric Quarterly*, *86*(4), 471–495. https://doi.org/10.1007/s11126-015-9347-5

Lockridge, Kenneth. A. (1974). *Literacy in colonial New England: An enquiry into the social context of literacy in the early modern West*. Norton & Company.

MacLeod, S., Musich, S., Gulyas, S., Cheng, Y., Tkatch, R., Cempellin, D., Bhattarai, G. R., Hawkins, K., & Yeh, C. S. (2017a). The impact of inadequate health literacy on patient satisfaction, healthcare utilization, and expenditures among older adults. *Geriatric Nursing*, *38*(4), 334–341. https://doi.org/10.1016/j.gerinurse.2016.12.003

MacLeod, S., Musich, S., Gulyas, S., Cheng, Y., Tkatch, R., Cempellin, D., Bhattarai, G. R., Hawkins, K., & Yeh, C. S. (2017b). The impact of inadequate health literacy on patient satisfaction, healthcare utilization, and expenditures among older adults. *Geriatric Nursing*, *38*(4), 334–341. https://doi.org/10.1016/j.gerinurse.2016.12.003

Malloy-Weir, L. J., Charles, C., Gafni, A., & Entwistle, V. (2016). A review of health literacy: Definitions, interpretations, and implications for policy initiatives. *Journal of Public Health Policy*, *37*(3), 334–352. https://doi.org/10.1057/jphp.2016.18

Martin, L. T., & Parker, R. M. (2011). Insurance expansion and health literacy. *Journal of the American Medical Association*, *306*(8), 874–875. https://doi.org/10.1001/jama.2011.1212

Marzilli, A. (2002). Controversy surrounds evidence-based practices. *The Key: National Mental Health Consumers' Self Help Clearing House Newsletter*, *7*(1).

McClain, G. R. (2012, January 2). *Healthcare Professionals: Acknowledging Emotional Reactions in Newly-Diagnosed Patients*. Just Got Diagnosed. https://justgotdiagnosed.com/resources/professionals-acknowledging-emotional-reactions-newly-diagnosed-patients/

McCormack, L., Thomas, V., Lewis, M. A., & Rudd, R. (2017). Improving low health literacy and patient engagement: A social ecological approach. *Patient Education and Counseling*, *100*(1), 8–13. https://doi.org/10.1016/j.pec.2016.07.007

Mclean, A. (2003). "Recovering" Consumers and a Broken Mental Health System in the United States: Ongoing Challenges for Consumers/Survivors and the New Freedom Commission on Mental Health Part II: Impact of Managed Care and Continuing Challenges by This is the second of a . *International Journal of Psychosocial Rehabilitation*, *8*, 58–70.

McNamara, J. (1996). Out of order: madnessis a feminist and a disability issue. In J. Morris (Ed.), *Encounters with strangers: Feminism and disability* (pp. 194–205). Women's Press.

McRuer, R. (2006). *Crip theory: cultural signs of queerness and disability /*. New York University Press.

Merry, L. A., Gagnon, A. J., Kalim, N., & Bouris, S. S. (2011). Refugee claimant women and barriers to health and social services post-birth. *Canadian Journal of Public Health*, *102*(4), 286–290.

Michener, H. A., & DeLamater, J. D. (1999). *Social psychology* (4th ed.). Harcourt, Brace.

Mitchell, S. E., Sadikova, E., Jack, B. W., & Paasche-Orlow, M. K. (2012). Health literacy and 30-day postdischarge hospital utilization. *Journal of Health Communication*, *17 Suppl 3*(October 2012), 325–338. https://doi.org/10.1080/10810730.2012.715233

Morgan, D., & Krueger, R. (1993). When to use focus groups and why. In D. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 3–19). SAGE Publications, Inc.

Morisky, D. E., Green, L. W., & Levine, D. M. (1986). Concurrent and predictive validity of a self-reported measure of adherence. *Medical Care*, *24*, 67–74.

Morrison, L. J. (2003). *Talking back to psychiatry: Resistant identities in the psychiatric consumer/survivor/ex-patient movement.* University of Pittsburgh.

Nabbali, E. M. (2009). A “mad” critique of the social model of disability. *Interpersonal Journal of Diversity in Organisations, Communities and Nations*, *9*(4), 1–12.

Nash, M. (2013). Diagnostic overshadowing: a potential barrier to physical health care for mental health service users. *Mental Health Practice*, *17*(4), 22–26. https://doi.org/10.7748/mhp2013.12.17.4.22.e862

National Association of Social Workers. (2008). *Code of Ethics*. http://www.socialworkers.org/pubs/code/code.asp

National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council. (2006). *Morbidity and mortality in people with serious mental illness table of contents* (J. Parks, D. Svendsen, P. Singer, & M. E. Foti, Eds.; Issue October 2006). National Association of State Mental Health Program Directors (NASMHPD) Medical Directors’ Council.

Newman, S. C., & Bland, R. C. (1991). Mortality in a cohort of patients with schizophrenia: A record linkage study. *Journal of Canadian Psychiatry*, *36*, 239–245.

Nguyen, T. H., Park, H., Han, H. R., Chan, K. S., Paasche-Orlow, M. K., Haun, J., & Kim, M. T. (2015). State of the science of health literacy measures: Validity implications for minority populations. In *Patient Education and Counseling* (Vol. 98, Issue 12, pp. 1492–1512). Elsevier Ireland Ltd. https://doi.org/10.1016/j.pec.2015.07.013

Nielsen-Bohlman, L., Panzer, A. M., & Kindig, D. A. (2004). *Health Literacy: A Prescription to End Confusion* (L. Nielsen-bohlman, A. M. Panzer, & D. A. Kindig, Eds.). National Academies Press.

Nordentoft, M., Wahlbeck, K., Hällgren, J., Westman, J., Ösby, U., Alinaghizadeh, H., Gissler, M., & Laursen, T. M. (2013). Excess Mortality, Causes of Death and Life Expectancy in 270,770 Patients with Recent Onset of Mental Disorders in Denmark, Finland and Sweden. *PLoS ONE*, *8*(1), e55176. https://doi.org/10.1371/journal.pone.0055176

Nutbeam, D. (2000). Health literacy as a public health goal : a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, *15*(3), 259–268.

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, *67*(12), 2072–2078. https://doi.org/10.1016/j.socscimed.2008.09.050

Oliver, M. A. (1990). *The politics of disablement: A sociological approach*. St. Martin’s Press.

Oliver, M. A., & Barnes, C. (1998). *Disabled people: From exclusion to inclusion*. Longman.

Osborn, D. P. J., Wright, C. a, Levy, G., King, M. B., Deo, R., & Nazareth, I. (2008). Relative risk of diabetes, dyslipidaemia, hypertension and the metabolic syndrome in people with severe mental illnesses: systematic review and metaanalysis. *BMC Psychiatry*, *8*, 84. https://doi.org/10.1186/1471-244X-8-84

Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013a). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, *13*(1). https://doi.org/10.1186/1471-2458-13-658

Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013b). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, *13*(1), 658. https://doi.org/10.1186/1471-2458-13-658

Paasche-Orlow, M. K., & Wolf, M. S. (2007). Literacy to Health Outcomes. *American Journal of Health Behavior*, *31 (Suppl)*, S19–S26.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: the unspoken connection. *Patient Education and Counseling*, *27*(1), 33–39.

Parker, R. M., Baker, D. W., Williams, M. V, & Nurss, J. R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, *10*(10), 537–541.

Parry, M. S. (2006). Ddorothea Dix (1802-1887). *American Journal of Public Health.*, *96*(4), 622–625. https://doi.org/10.2105/AJPH.96.4.622

Parsons, T. (1951). *The Social System*. Free Press.

Pembroke, L. (Ed.). (1994). *Eating distress: Pespectives from personal experience*. Survivors Speak Out.

PIAAC. (2014). *What the Data Say About the Skills of U . S . Adults* (Issue October 2013).

Plain Writing Act of 2010, Pub. L. No. 124 STAT 2861 (2010).

Poole, J. M., Jivraj, T., Arslanian, A., Bellows, K., Chiasson, S., Hakimy, H., Pasini, J., & Reid, J. (2012). Sanism, 'mental health', and social work/education: A review and call to action. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice*, *1*(1), 20–36.

Prager, E., & Tanaka, H. (1979). A client-developed measure (CDM) for self-assessment and change for outpatient mental health services. In *New Research in Mental Health*. Ohio Department of Mental Health.

Qualtrics. (2005). Qualtrics.

Rapley, M. (2001). Policing happiness. In *This is Madness Too: Critical Perspectives on Mental Health Services* (pp. 35–46). PCCS Books.

Reid, N. (1996). Testing the test: Wide Range Achievement Test 1984 revised edition. *Journal of Counseling & Development*, *64*, 538–539.

Ridgway, P. A. (1988). *The voice of Users/Consumers/Surivvors in Mental HealthSystems: a call for change*.

Ridgway, P. A. (2001). Restorying Psychiatric Disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, *24*(4), 335–343.

Rikard, R. v., Thompson, M. S., McKinney, J., & Beauchamp, A. (2016a). Examining health literacy disparities in the United States: A third look at the National Assessment of Adult Literacy (NAAL). *BMC Public Health*, *16*(1). https://doi.org/10.1186/s12889-016-3621-9

Rikard, R. v., Thompson, M. S., McKinney, J., & Beauchamp, A. (2016b). Examining health literacy disparities in the United States: A third look at the National Assessment of Adult Literacy (NAAL). *BMC Public Health*, *16*(1). https://doi.org/10.1186/s12889-016-3621-9

Roberts, G. A. (2000). Narrative and severe mental illness: what place do stories have in an evidence-based world? *Advances in Psychiatric Treatment*, *6*(6), 432–441. https://doi.org/10.1192/apt.6.6.432

Rosas-Salazar, C., Apter, A. J., Canino, G., & Celedón, J. C. (2012). Health literacy and asthma. *Journal of Allergy and Clinical Immunology*, *129*(4), 935–942. https://doi.org/10.1016/j.jaci.2012.01.040

Rose, L. E., Sawyer, A. L., & Everett, A. (2014). Cardiovascular health literacy and treatment adherence in persons with serious mental illness. *Issues in Mental Health Nursing*, *35*(2), 88–99.

Rosenberg, S. D., Goodman, L. A., Osher, F. C., Swartz, M. S., Essock, S., Butterfield, M. I., Constantine, N. T., Wolford, G. L., & Salyers, M. (2001). Prevalence of HIV, Hepatitis B, and Hepatitis C in people with severe mental illness. *American Journal of Public Health*, *91*(1), 31–38.

Sartorius, N. (2002). Iatrogenic stigma of mental illness. *BMJ*, *324*(7352), 1470–1471. https://doi.org/10.1136/bmj.324.7352.1470

Schaffler, J., Leung, K., Tremblay, S., Merdsoy, L., Belzile, E., Lambrou, A., & Lambert, S. D. (2018a). The effectiveness of self-management interventions for individuals with low health literacy and/or low income. *Journal of General Internal Medicine*, *33*, 510–523.

Schaffler, J., Leung, K., Tremblay, S., Merdsoy, L., Belzile, E., Lambrou, A., & Lambert, S. D. (2018b). The Effectiveness of Self-Management Interventions for Individuals with Low Health Literacy and/or Low Income: A Descriptive Systematic Review. In *Journal of General Internal Medicine* (Vol. 33, Issue 4, pp. 510–523). Springer New York LLC. https://doi.org/10.1007/s11606-017-4265-x

Scharf, M. (2007). Long-term effects of trauma: psychosocial functioning of the second and third generation of Holocaust survivors. *Development and Psychopathology*, *19*(2), 603–622. https://doi.org/10.1017/S0954579407070290

Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling*, *52*(3), 315–323. https://doi.org/10.1016/S0738-3991(03)00107-1

Schillinger, D., Piette, J., Grumbach, K., Wang, F., Wilson, C., Daher, C., Leong-grotz, K., Castro, C., & Bindman, A. B. (2003). Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*, *163*, 83–90. https://doi.org/10.1001/archinte.163.1.83.

Scott, T. L., Gazmararian, J. A., Williams, M. V, & Baker, D. W. (2002). Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care*, *40*(5), 395–404.

Selden, C. R., Zorn, M., Ratzan, S., & Parker, R. M. (2000). *Current Bibliographies in Medicine: Health Literacy*. Department of Health and Human Services; National Institutes of Health; National Library of Medicien.

Sentell, T. L., & Shumway, M. A. (2003). Low literacy and mental illness in a nationally representative sample. *The Journal of Nervous and Mental Disease*, *191*(8), 549–552.

Serper, M., Patzer, R. E., Curtis, L. M., Smith, S. G., O'Conor, R., Baker, D. W., & Wolf, M. S. (2014). Health literacy, cognitive ability, and functional health status among older adults. *Health Services Research*, *49*(4), 1249–1267. https://doi.org/10.1111/1475-6773.12154

Shefer, G., Henderson, C., Howard, L. M., Murray, J., & Thornicroft, G. (2014). Diagnostic overshadowing and other challenges involved in the diagnostic process of patients with mental illness who present in emergency departments with physical symptoms - a qualitative study. *PloS One*, *9*(11), e111682. https://doi.org/10.1371/journal.pone.0111682

Sherraden, M., Barth, R. P., Brekke, J., Fraser, M. W., Manderscheid, R., & Padgett, D. K. (2014). *Social Is Fundamental: Introduction and Context for Grand Challenges for Social Work.*

Sherraden, M., Stuart, P., Barth, R. P., Kemp, S., Lubben, J., Hawkins, J. D., Coulton, C., Mcroy, R., Walters, K., Healy, L., Rutgers, B. A., Mahoney, K., Brekke, J., Padilla, Y., Dinitto, D., Padgett, D., Schroepfer, T., & Catalano, R. (2015). *Grand Accomplishments in Social Work Grand Challenges for Social Work Initiative*.

Silva, M., Nunes, S., Macedo, P., Figueiredo, A., Fornelos, A., & Maia, D. (2015). "It's psychiatric!" About stima in general hospital. *Global Mental Health*, 1.

Silverman, D. (1993). *Inerpreting qualitative data: Methods for analysing talk, text, and interaction*. Sage.

Sleath, B. L., Jackson, E., Thomas, K. C., Galloway, J., Dumain, L., Thorpe, J., Rollins, A., & Morrissey, J. (2006). Literacy and perceived barriers to medication taking among homeless mothers and their children. *American Journal of Health-System Pharmacy*, *63*(4), 346–351. https://doi.org/10.2146/ajhp050070

Smith, J. A., & Shinebourne, P. (2012). Interpretative phenomenological analysis. In *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological.* (pp. 73–82). American Psychological Association. https://doi.org/10.1037/13620-005

Smith, M. K., & Ford, J. (1986). Client involvement: practical advice for professionals. *Psychosocial Rehabilitation Journal*, *9*(3), 25–34.

Smith, S. A., & Moore, E. J. (2012). Health Literacy and depression in the context of home visitation. *Maternal and Child Health Journal*, *16*(7), 1500–1508. https://doi.org/10.1007/s/10995-011-0920-8

Solomon, S. D., & Davidson, J. R. (1997). Trauma, prevalence, impairment, service use, and cost. *The Journal of Clinical Psychiatry*, *58*(Supp 9), 5–11.

Sørensen, K., van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*, *12*(1), 80. https://doi.org/10.1186/1471-2458-12-80

Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health*, *12*(1), 80. https://doi.org/10.1186/1471-2458-12-80

Soto Mas, F., & Jacobson, H. E. (2019). Advancing Health Literacy Among Hispanic Immigrants: The Intersection Between Education and Health. *Health Promotion Practice*, *20*(2), 251–257. https://doi.org/10.1177/1524839918761865

Sprague, J., & Hayes, J. (2000). Self-determination and empowerment: a feminist standpoint analysis of talk about disability. *American Journal of Community Psychology*, *28*(5), 671–695.

Stein, B. D., Kogan, J. N., Mihalyo, M. J., Schuster, J., Deegan, P. E., Sorbero, M. J., & Drake, R. E. (2013). Use of a computerized medication shared decision making tool in community mental health settings: impact on psychotropic medication adherence.

Community Mental Health Journal, *49*(2), 185–192. https://doi.org/10.1007/s10597-012-9528-8

Stewart, H., Jameson, J. P., & Curtin, L. (2015). The relationship between stigma and self-reported willingness to use mental health services among rural and urban older adults. *Psychological Services*, *12*(2), 141–148.

Strega, S. (2005). The view from the poststructural margins: Epistemology and methodology resistance. In L. Brown & S. Strega (Eds.), *Research as Resistance* (pp. 199–234). Canadian Scholars' Press.

Substance Abuse and Mental Health Adminstration (SAMHSA). (2012). *Results from the 2011 National Survey on Drug Use and Health: Mental Health Findings NSDUH Series H-45, HHS Publication No. (SMA) 12-4725.*

Sullivan, G., Han, X., Moore, S., & Kotria, K. (2006). Disparities in hospitalization for diabetes among persons with and without co-occurring mental disorders. *Psychiatric Services*, *57*(8), 1126–1131.

Sullivan, G., Han, X., Moore, S., & Kotrla, K. (2006). Disparities in hospitalization for diabetes among persons with and without co-occurring mental disorders. *Psychiatric Services*, *57*(8), 1126–1131. https://doi.org/10.1176/appi.ps.57.8.1126

Sullivan, G., Koegel, P., Kanouse, D. E., Cournos, F., McKinnon, K., Young, A. S., & Bean, D. (1999). HIV and people with serious mental illness: The public sector's role in reducing HIV risk and improving care. *Psychiatric Services*, *58*, 648–652.

Sweeney, A. (2009). So What is Survivor Research? In A. Sweeney, P. Beresford, A. Faulkner, M. Nettle, & D. Rose (Eds.), *This Is Survivor Research* (pp. 22–37). PCCS Books.

Sweeney, A. (2013). Sociology and survivor research: an introduction. In P. Staddon (Ed.), *Mental Health Service Users in Research: Critical sociological perspectives* (pp. 1–10). Policy Press.

Sweeney, A., Beresford, P., Faulkner, A., Nettle, M., & Rose, D. (Eds.). (2009). *This is Survivor Research*. PCCS Books.

Szatmari, P. (1999). Evidence-based child psychiatry and the two solitudes. In *Evidence-Based Mental Health* (Vol. 2, Issue 1, pp. 6–7). https://doi.org/10.1136/ebmh.2.1.6

TenHave, T. R., Van Horn, B., Kumanyika, S., Askov, E., Matthews, Y., & Adams-Campbell, L. L. (1997). Literacy assessment in a cardiovascular nutrition education setting. *Patient Education and Counseling*, *31*(2), 139–150.

Tew, J. (2005). Core themes of social perspectives. In J. Tew (Ed.), *Social Perspectives in Mental Health* (pp. 13–31). Jessica Kingsley Publishers.

The President's New Freedom Commission on Mental Health. (2003). *Achieving the Promise: Transforming Mental Health Care in America.*

Thornicroft, G. (2011). Physical health disparities and mental illness: the scandal of premature mortality. *The British Journal of Psychiatry*, *199*, 441–442. https://doi.org/10.1192/bjp.bp.111.092718

Thornicroft, G., Rose, D., & Kassam, A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry*, *19*(2), 113–122. https://doi.org/10.1080/09540260701278937

Thornicroft, G., & Tansella, M. (2011). Growing recognition of the importance of service user involvement in mental health service planning and evaluation. *Epidemiologia e Psichiatria Sociale*, *14*(01), 1–3. https://doi.org/10.1017/S1121189X00001858

Tones, K. (2002). Health literacy: new wine in old bottles? *Health Education Research*, *17*(3), 287–290.

Turner, M., & Beresford, P. (2005). *User-controlled research: Its meanings and Final Report*.

Tyrer, P. (2003). *Models for mental disorder: Conceptual models in psychiatry.* (3rd ed.). John Wiley.

Uehara, E. S., Barth, R. P., Catalano, R. F., Hawkins, J. D., Kemp, S. P., Nurius, P. S., Padgett, D. K., & Sherraden, M. (2014). *Identifying and Tackling Grand Challenges for Social Work Grand Challenges for Social Work Initiative*.

Union of the Physically Impaired Against Segregation (UPIAS). (1976). *Fundamental principles of disability.* Union of the Physically Impaired Against Segregation.

University of Texas, A. (1976). *Adult Performance Level Test*.

U.S. Department of Education National Center for Education Statistics. (2019, July). *Adult literacy in the United States*. Data Point. https://web.archive.org/web/20200730223012/https:/nces.ed.gov/datapoints/2019179.asp

Usher, W. (2011). Types of social media (Web 2.0) used by Australian allied health professionals to deliver early twenty-first-century practice promotion and health care. *Social Work in Health Care*, *50*(4), 305–329. https://doi.org/10.1080/00981389.2010.534317

van Melle, L. P., De Jonge, P., Spijkerman, T. A., Tijssen, J. g.P., Ormel, J., van Veldhuisen, D. J., van den Brink, R. H., & van de Berg, M. P. (2004). Prognostic association of depression following myocardial inifarction with mortality and cardiovascular events; a meta-analysis. *Psychosocial Medicine*, *66*, 814–822.

van Nieuwenhuizen, a, Henderson, C., Kassam, A., Graham, T., Murray, J., Howard, L. M., & Thornicroft, G. (2013). Emergency department staff views and experiences on diagnostic overshadowing related to people with mental illness. *Epidemiology and Psychiatric Sciences*, *22*(3), 255–262. https://doi.org/10.1017/S2045796012000571

Wallcraft, J., & Bryant, M. (2003). *The mental health service user movement in England*. Sainsbury Centre for Mental Health.

Wallcraft, J., & Nettle, M. (2009a). History, Context and Language. In J. Wallcraft, B. Schrank, & M. Amering (Eds.), *Handbook of Service User Involvement in Mental Health Research*. Wiley-Blackwell.

Wallcraft, J., & Nettle, M. (2009b). History, Context and Language. In J. Wallcraft, B. Schrank, & M. Amering (Eds.), *Handbook of Service User Involvement in Mental Health Research* (pp. 1–12). Wiley-Blackwell.

Wallcraft, J., Read, J., & Sweeney, A. (2003). *On our own Terms: Users and survivors of mental health services working together for support and change*. Sainsbury Centre for Mental Health.

Wallston, K. a., Cawthon, C., McNaughton, C. D., Rothman, R. L., Osborn, C. Y., & Kripalani, S. (2013). Psychometric properties of the Brief Health Literacy Screen in clinical practice. *Journal of General Internal Medicine*, *29*(1), 119–126. https://doi.org/10.1007/s11606-013-2568-0

Watkins, L. L., Koch, G. G., Sherwood, A., Blumenthal, J. A., Davidson, J. R. T., O'Connor, C., & Sketch, M. H. (2013). Association of anxiety and depression with all cause mortality in individuals with coronary heart disease. *Journal of the American Heart Association*, *2*(2), e000068. https://doi.org/10.1161/JAHA.112.000068

Weisfeld, A., & Perlman, R. L. (2005). Disparities and discrimination in health care: An introduction. *Perspectives in Biology and MEdicine*, *48*(1), 1-S9. https://doi.org/10.1353/pbm.2005.0046

Weiss, B. D., & Coyne, C. (1997). Communicating with patients who cannot read. *New England Journal of Medicine*, *337*, 272–273.

Weiss, B. D., Mays, M. Z., Castro, K. M., DeWalt, D. A., Pignone, M. P., Mockbee, J., & Hale, F. A. (2005). Quick Assessment of Literacy in Primary Care: The Newest Vital Sign. *Annals f Family Medicine*, *3*(6), 514–522. https://doi.org/10.1370/afm.405.College

Weiss, B. D., & Palmer, R. (2004). Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *The Journal of the American Board of Family Practice*, *17*(1), 44–47.

Whitaker, R. (2002). *Mad in America: Bad science, bad medicine and the enduring mistreatment of the mentally ill.* Perseus.

Williams, G. (1998). The sociology of disability: Towards a materialist phenomenology. In T. Shakespeare (Ed.), *The Disability Reader: Social science perspectives* (pp. 234–244). Cassell.

Williams, M. V, Baker, D. W., Parker, R. M., & Nurss, J. R. (1998). Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease. *Archives of Internal Medicine*, *158*(2), 166–172. https://doi.org/10.1001/archinte.158.2.166

Willis, J. (2009). Health literacy: new packaging for health education or radical movement? *International Journal of Public Health*, *54*(1), 3–4.

Wilson, A., & Beresford, P. (2002). Madness, distress and postmodernity: Putting the record straight. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity: Emobodying disability theory* (pp. 143–158). The Chromwell Press.

Winter, J. A. (2003). The development of the Disability Rights Movement as a social problem solver. *Disability Studies Quarterly*, *23*(1), 33–61.

Wong, F. K., & Poon, A. (2010). Cognitive behaviorual group teratment for Chinese parents with children with developmental disabilities in Melbourne, Australia: An efficacy study. *Australian & New Zealand Journal of Psychiatry*, *44*(8), 742–749. https://doi.org/10.3109/00048671003769769

Woodcock, R. (1977). *The Woodcock-Johnson Psycho-Educational Battery.* DLM Teaching Resources.

Yanos, P. T., Stanley, B. S., & Greene, C. S. (2009). Research risk for persons with psychiatric disorders: A decisional framework to meet the ethical challenge. *Psychiatric Services*, *60*(3), 374–383. https://doi.org/10.1176/appi.ps.60.3.374.Research

Ylitalo, K. R., Meyer, M. R. U., Lanning, B. A., During, C., Laschober, R., & Griggs, J. O. (2018). Simple screening tools to identify limited health literacy in a low-income patient population. *Medicine (United States)*, *97*(10). https://doi.org/10.1097/MD.0000000000010110

Zanchetta, M. S., R., M. P., W., G.-G., da Cunha, Z., Cordeiro, H. A., Fagundes-Filho, F. E., Pinho, M. A., Voet, S. M., Talbot, Y., Caldas, R. S., de Souza, T. J., & Costa, E. (2014). Brazillian community health agents and qualitative primary healthcare information. *Primary Health Care Research & Development*, 1–11.

Zaslow, M. J., Ma, M. R. D., Sargent, J., & Hair, E. C. (2001). Maternal Depressive Symptoms and Low Literacy as Potential Barriers to Employment in a Sample of Families Receiving Welfare: Are There Two-Generational Implications? *Women & Health*, *32*(3), 211–251. https://doi.org/10.1300/J013v32n03

Zola, & Irving, K. (1983). Developing new self-images and interdependence. In N. M. Crewe, Zola & Associates, & K. Irving (Eds.), *Independent living for phsyically disabled people* (pp. 49–59). Jossey-Bass.