

# **Fostering Self-Determination as a Means to Recovery**

BY

MARY E. MAHAFFEY

B.S., University of Wisconsin, Madison, 1984

M.S., University of Illinois at Chicago, Chicago, 1992

DISSERTATION

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Defense Committee:

Yolanda Suarez-Balcazar, Chair and Advisor

Sarah Parker Harris

Tamar Heller

Susan Magasi, Occupational Therapy

Linda Olson, Rush University

*I dedicate this project to the 12 people who gave me their time and their views throughout the 6 months that we met together. This wonderful group of people dedicated nearly 25 hours of their time to this project. I will never forget the enjoyable discourse during the groups, the great conversation over treats and the laughs we had. I hope our alliance can continue in some capacity.*

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## **LIST OF ABBREVIATIONS**

ACT	Assertive Community Treatment
ADA	American with Disabilities Act
CBPR	Community-Based Participatory Research
CI	Collaborative Inquiry
DSM	Diagnostic and Statistical Manual
EBP	Evidence-Based Practice
IDHS	Illinois Department of Human Services
IRB	Institutional Review Board
IMD	Institute of Mental Diseases
KT	Knowledge Translation
MFP	Money Follows the Person
NCD	National Council on Disability
PA	Personal Assistant
PADs	Psychiatric Advanced Directives
PAR	Participatory Action Research
PP	Peer (Service) Provider
SAG	Social Action Group
SAMSHA	Substance Abuse and Mental Health Services Administration
SDC	Self-Directed Care
SDT	Self-Determination Theory
SP	Service Provider (professional)
SU	Service User

## **LIST OF ABBREVIATIONS (continued)**

WRAP	Wellness Recovery Action Plan
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## SUMMARY

Mental health service providers have increasingly identified self-determination as a goal of the service relationship. Despite that goal, the literature continues to describe a power relationship that favors providers and provider systems and limits access to self-determination. This study explores how a group of service users and providers from a community mental health center in Illinois, develop a shared understanding of disability from a civil and human rights perspective as a way to foster self-determination.

The study used an emancipatory approach called collaborative inquiry (CI). CI is a participatory research method that uses cycles of action and reflection to introduce new ideas and concepts and then reflect on what was learned. Participants completed individual interviews to determine their baseline understanding of disability, disability rights, and self-determination. Participants then attended 11 groups, one introductory reflection group and five monthly CI cycles of action and reflection. During the action groups participants were taught concepts of disability studies models and disability rights. Reflection groups followed one week later. The interviews and reflection groups were audio recorded, transcribed, and coded using a process of inductive thematic analysis. Trustworthiness was achieved through member checking and review of themes and subthemes by two people who were not associated with the study.

The analysis of the data revealed seven overarching themes including: Disability is in the person, barriers to community participation, power relationships, stigma around psychiatric disability, rethinking disability, humanity within disability, and toward the future: “So What, Now What.” Service users felt the information increased their sense of self-determination and their confidence as disabled people. They appreciated learning

## **SUMMARY (continued)**

about disability rights and found the social model changed their understanding of disability. Professionals and peer providers stated they are paying attention to, and addressing the social supports and barriers to living with psychiatric disability. Participants found the small group activities and discussions gave them greater insight around long held beliefs, about each other and about the helping relationship. The results of this study suggest that proponents of stigma reduction must reconsider their reliance on the use of overcoming illness stories. This study suggests that these stories serve only to increase the public's perception of the seriousness or dangerousness of psychiatric disability.

There are several implications from this study. People with psychiatric disabilities and those who serve them would benefit from learning about the social model of disability and disability from a civil and human rights perspective. A curriculum for introducing service users and providers to disability and mad studies, combined with a CI approach, would be an effective way to present this information and would allow for continued research on whether learning about disability studies helps foster self-determination and a sense of empowerment. To be effective, it is suggested the psychiatric disability studies curriculum include modules on invisible disability and rewriting narrative stories to reflect art, culture, and shared disability history. The results also imply that Recovery Model interventions may be more effective at affording self-determination if they include training and action items around social and civil rights approaches to disability.

## I. INTRODUCTION

### A. **Background Information**

In 1999 the Supreme Court made a landmark decision when it ruled against the state of Georgia in a 6-3 ruling stating that keeping people in institutions was a violation of Title 2 of the American with Disabilities Act (ADA, 1990). *Olmstead vs L.C. and E.W.* (1999) or what is commonly referred to as the Olmstead decision ruled that public agencies must provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Several years after the decision, the Department of Justice started bringing lawsuits against states who were not providing the services people with disabilities needed in accordance with the law. To avoid costly litigation states, including Illinois, agreed to enter into consent decrees in which the courts would monitor efforts to relocate and serve people who wanted to move out of institutions. Between the consent decrees and federal funding through a demonstration project called Money Follows the Person (MFP), (Morris, et al., 2014), states began to redirect money into community based mental health services and these organizations started moving people with disabilities, including psychiatric disabilities, out of institutions and into the communities of their choice (Illinois Department of Human Services, Department of Mental Health (IDHS-DMH, 2011).

As a requirement of the Money Follows the Person (MFP) initiative, researchers are collecting data to determine the impact and outcome of the project. Preliminary data indicate that in general people with psychosocial disability experience a greater sense of overall satisfaction in their lives after the transition (Morris, et. al., 2014). Despite that claim more than half of people eligible are not transitioning into the community. There are two commonly cited barriers for people not transitioning. The first barrier is that some of the people who express interests in

moving out are determined ineligible by the state reviewers because the assessment indicates they have service needs beyond the capacity of the current community mental health provider system. The second barrier is that around 50% of those who are referred for transition and community based services are refusing to participate in the assessments because either they believe they cannot manage community living or they believe the services they need are not available. Others are refusing transition even after they are approved for the program (Jones, 2017). Of those who have moved out of institutions the majority have maintained community tenancy with only 14% returning to institutions (Jones, 2017).

The people who have transitioned from institutions to the community report varying levels of satisfaction with community living. MFP data indicate that the majority of people state they are more satisfied with their lives after their transition out of the institutions (Morris et al., 2014). However, there are still some important aspects of their new lives they find dissatisfying, such as access to desirable housing options and adequate transportation. One of the most important factors is that people do not feel they are an integral part of their new communities (Jones, 2014; Minkler, Hammel, Gill, Magasi, Breckwich, Bristo, & Colema, 2008).

## B. **Statement of the Problem**

The Recovery Process Model has become widely accepted in mental health service systems and is the basis for community mental health intervention programs throughout the country. Within that model self-determination is highlighted as an important value (Allness & Knoedler, 2003), yet poor treatment adherence continues to be cited as a primary reason for institutional recidivism (Corrigan, 2011). Service provision for people with severe and persistent psychiatric impairment remains grounded in the medical model which purports that people with psychosocial disability must comply with prescribed interventions to be successful. People are

often expected to prove they are safe and competent before they can experience the basic human right of community living (Corrigan, 2011; Lunt, 2004; Tsemberis & Eisenberg, 2000).

Research conducted through MFP indicates that community support programs provide risk assessment and mitigation interventions that address basic daily physical and mental needs. These include systems to make sure people take medications correctly, manage their money effectively, shop for groceries, maintain their apartments, and function as good tenants (Forchuk, Nelson, & Hall, 2006; Morris et al., 2014). What community support programs do not address effectively is the impact that institutionalism has on the person's ability to maintain the social supports they had before going into the institution, or to develop the social capital necessary for satisfactory community tenancy after leaving. People who have lived in nursing homes for long periods of time are not necessarily involved in the day-to-day decision making needed to run their lives. The result is loss of autonomy and confidence when it comes to asking for the supports and seeking the resources they require to establish a satisfactory life in the community. Lastly, few have learned the self-preservation skills needed to navigate a societal structure that stigmatizes and marginalizes people with psychiatric disability (Forchuk, Nelson, & Hall, 2006). For these reasons people with psychiatric disability are ill equipped to be self-determined and they are compelled to look to providers for direction (Jones, 2017; Minkler et al. 2008).

### C. **Significance of the Problem**

Self-Determination is a critical factor in the process of recovery for persons with psychosocial disability (Davidson & Roe, 2007). Deci and Ryan (2000) define the theory of self-determination (SDT) as a collection of mini-theories that when considered together explain the relationship of basic psychological need to all the domains of human behavior. The crux of SDT is motivation, portrayed as a hierarchical continuum ranging from a-motivation, to extrinsic

motivation and then to the desired intrinsic motivation. According to SDT, intrinsic motivation and subsequently the sense of self-determination is achieved when a person experiences fulfillment of three basic needs. The first is the need for competence, described as the ability to express one's capabilities resulting in a sense of effectiveness within the social environment. The second is relatedness, which refers to having a sense of belongingness or connection to others in the social environment. The last is autonomy defined as experiencing the self as the origin of one's own behavior. According to the SDT when these three needs are met a person achieves greater psychological health, well-being and satisfactory functioning in day-to-day activities (Deci & Ryan, 2000).

Self-determination theory fits well with the Recovery Process Model, a model that is increasingly used to inform state mental health initiatives around people with psychosocial disabilities (Davidson, Rowe, Tondora, O'Connell, & Lawless, 2008). The Recovery Process Model is a model built through a consensus process based on a collection of phenomenological studies with people who self-identify as being "in recovery" after being diagnosed with severe and persistent psychosocial disability (Jacobson & Greenly, 2001). Like SDT, the Recovery Process Model is a set of mini-theories that together define the non-linear and varied course of psychosocial recovery ranging on a continuum from complete cure to persistent disability. Most important to this model is the focus on participation in important aspects of daily life, regardless of the existence of symptoms of psychiatric impairment. There are several versions of the recovery model available in the literature though all share important aspects that fit closely with the three basic needs of autonomy, competence, and relatedness defined in SDT (Bellack, 2006; Davidson et al., 2008; Jacobson & Greenly, 2001). In particular, the Recovery Process Model asserts that recovery is possible only in a system that nurtures self-direction, empowerment and



hope; allows people to take responsibility for their actions and engage in meaningful daily life roles including taking risks and making mistakes; and fosters mutual respect within the community (Bellack, 2006; Burgess, Pirkis, Combs, & Rosen, 2010; Davidson et al., 2008; Jacobson & Greenly, 2001).

Community mental health programs are shifting to intervention models that include self-management programs as a way to encourage recovery and self-determination. A meta-analysis of 13 studies on self-management programs completed in 2013 revealed that people who created their own intervention plans through a shared decision-making process showed significantly greater autonomy and responsibility when dealing with the disabling factors associated with their psychiatric impairments (Zou, Li, Nolan, Arthur, Wang, & Hu, 2012). Self-management interventions that include education and share-decision making, such as Living Well (Goldberg et al., 2013). Wellness Action Recovery Planning (WRAP) (Cook et al., 2012; Copeland, n.d), and Psychiatric Advanced Directives (PADS) (Scheyett & Kim, 2007) are designed to shift the power in the intervention process to the person with psychosocial disability. These programs are meant to provide people the opportunity to take risks in their recovery while maintain a safety net.

Interventions provided by Peer Support Specialist, such as peer provided case management and WRAP, are identified as an integral part of the self-determination portion of the Recovery Process Model (Substance Abuse and Mental Health Services Administration, 2012). The Substance Abuse and Mental Health Services Administration (SAMHSA) defines Peer Support Specialist as individuals with lived experience of recovery from mental health or substance abuse issues, who have developed skills through specialized training to provide services that promote “mind-body recovery and resilience” (Substance Abuse and Mental Health

Services Administration, n.d.). Research on peer provided intervention indicates that peer providers experience positive outcomes in their own recovery after they are trained and begin to serve as providers, but for those receiving peer services the effect on recovery remains unclear (Chinman et al. 2014; Hutchinson et al. 2006). Davidson, Chinman, Sells and Rowe (2006) identify several concerns that arise regarding peer provision of services. For example, the power of reciprocal support that occurs from the friendships and shared experiences between peers is undermined when peer-providers join a clinical team. On these teams, peer providers are expected to observe the same rules of professional interaction as professional providers. These rules require that providers maintain personal boundaries which restrict peers from developing friendships and sharing of personal experience. Peer providers often assume the same one-directional model of care as professional providers (Davidson, Chinman, Sells, & Rowe, 2006).

Applying a critical disability studies lens brings to light several counterproductive tendencies in the current mental health system. According to Corrigan et al., (2012) adherence to prescribed treatments by people with psychosocial disability remains low, often due to the effects of the medications on their health and functional ability. A request to stop uncomfortable medical intervention is labeled by providers as non-compliant, rather than seen as an opportunity to explore options and exercise self-determination. Davidson and McGlashan (1997) state that treatment decisions in the medically informed mental health system are based on symptoms of pathology. This is problematic given there is significant variation in how disorders and symptomology are constructed and applied in theory, medicine, and research (McGruder, 2002). In addition, there are limitations to seeing symptoms as a product of brain disease and dismissing the potential impact of an unaccommodating and often traumatic social and physical environment. The authors point out that determination of pathology based on reports of psychiatric

symptomology often leads to ambiguous diagnostic decisions that can feel arbitrary to the person and their families, and to the community at large (Davidson & McGlashan, 1997). Davidson, Staynor, Nichou, Styron, Rowe, and Chinman (2001) write that despite centuries of effort nobody has found a cure for those with persistent psychosocial impairment yet unlike those with permanent physical impairment, they are expected to achieve a high level of “normalcy” before they are included in society. Lunt (2004) points out that what is often labeled as non-compliance is a clash between the values of the provider and the values of the person with disability. Given all of this it makes sense that treatment decisions imposed on people with the intent of decreasing their pathology, are likely to be considered with ambivalence. Add to that the powerful rhetoric that equates a safer society with “compliant patients” and it becomes clear why people with psychiatric disabilities struggle to develop a sense of competence and autonomy and are more extrinsically motivated – in effect the expectation of adherence extinguishes self-determination (Deci & Ryan, 2000).

Consequently, removing all the barriers to self-determination will require that both actors, the service providers and the service users, develop a greater awareness of those barriers, and cultivate a more collaborative approach to mental health services. Education programs that address each of these groups separately have not considered the interdependence of these players. Intervention programs such as PADs have given service users a greater voice in their care decisions when they are in crisis, but they have not actually shifted the power relationship in the day-to-day services. For that reason, development of intrinsic motivation needed for self-agency and ultimately better psychological health for people with psychosocial disability remains an elusive goal (Davidson et al., 2001; Scheyett & Kim, 2007).

The Recovery movement sparked the development of a number of intervention programs designed to facilitate the fostering of self-determination around community living issues for people with mental illness (Cook et al., 2012; Copeland, n.d.; Scheyett & Kim, 2007). All of these programs are focused on supporting decision making and choice around personal responsibility for the disorder and services. Few of the programs consider social barriers to community participation or disability rights. One program that does focus on these issues is the MFP Stepping Stones program. MFP Stepping Stones is an Illinois state demonstration program devised specifically for people with disabilities who are living in nursing homes in Chicago, IL, and have become eligible for community-based services as a result of the Olmstead decision (Lee, Hammel, Wilson, & Jansa, 2008). The Stepping Stones program includes ten modules that address the barriers to community living identified through a larger community-based participatory research project called Moving Out of the Nursing Home (Lee, Hammel, & Wilson, 2016). Stepping Stones addresses community living skills such as using technology, money management, housing, self-management, wellness, and building a social support network. Two of the modules are designed to help people with disabilities reframe the concept of disability from a medical/impairment approach to a social and civil rights approach. Although all the modules are applicable to people with psychosocial impairment, the films and examples are heavily focused on physical disability and none of the modules address barriers specific to living with a psychosocial disability. For example, although the modules address the issue of disability stigma, they do not effectively address hidden disability, or the stripping of basic human and civil rights that happens when someone is considered to have poor reasoning and judgment and how society has come to define people with psychosocial disability as dangerous (Price, 2011; Corrigan & Lundin, 2001). The Stepping Stoned program is described in more detail in Chapter I

#### D. **Study Purpose**

This research project brings together service users and service providers from the Kankakee Thresholds community mental health center, to explore the system of care through a disability rights perspective. The project utilizes a curriculum called MFP Stepping Stones: A Community Living Management Program for People with Disabilities Who Moved Out of Nursing Homes (Lee, Hammel, Wilson, & Jansa, 2008), as a way to engage service users and service providers in a dynamic intervention process of reflection and discussion around issues of access to self-determination. This curriculum explores the impact of health, economic, housing and disability rights policies as well as prevailing social beliefs on independence for people with all different disabilities, including psychosocial disability. Participants, which include consumers and providers, review the curriculum together and reflect on what they learn about the forces impacting access to self-determination for individuals with psychosocial disability.

This study was designed to answer the following primary research question: How do service users and service providers co-create a shared understanding of disability through a civil and human rights perspective, as a way to foster self-determination for people with psychosocial disability? In the original proposal of this dissertation project, there were two additional questions focused on the impact of the intervention which included: Does the shared task of adapting the Stepping Stones program modules to reflect on psychosocial disability result in a discourse that reflects greater awareness of the power relationship between users and providers in the study and in the community-based delivery model? And do the suggested changes to the Stepping Stones program reflect a shared understanding of disability from a civil and human rights perspective? The study used a Collaborative Inquiry method for data collection. Collaborative Inquiry (CI) is a participatory, action-based inquiry process that promotes

knowledge translation (Bray, Lee, Smith, & Yorks, 2000). CI engages participants through a series of action and reflection cycles. During action phases participants are introduced to new ideas and learning. During reflection phases participants discuss how that new learning impacts their thinking and practice. In response to input from the research participants, the CI process focused mainly on the primary research question. As a result, not enough data was available to answer the two additional questions. The following chapter (II) discusses in detail the body of literature available on self-determination for people with mental illness, the Stepping Stones program, and participatory methodologies designed to promote reflection, including Collaborative Inquiry.

## **II. CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW**

Changing the mental health services system means challenging a hegemonic belief that psychiatric differences are at best a challenging personal medical issue, and at worst a dangerous social threat that must be managed through medical interventions and containment. People with psychiatric disabilities are often expected to comply with behavioral standards established by people without psychiatric disabilities and by society's idea of "normative behavior." When they do they are rewarded with privileges that most people take for granted as human rights such as choosing where they want to live. This study challenges scholars to rethink psychiatric disability as a broader and more complex phenomenon.

In the formal mental health services system, there are two prevailing models of intervention; the medical model and the Recovery Process Model. Outpatients, acute care, and crisis systems rely on medication and counseling. Community-based mental health systems tend to focus more on community support teams that have adopted the Recovery Process Model as a guiding theoretical approach. Self-determination Theory (SDT), often referred to as client-centered or even client-driven, is claimed by all camps. Scholars in Disability and Mad studies are challenging the claim that the medical model, or even the Recovery Process Model given how it is used today, provides access to true self-determination. A societal understanding of psychiatric disability, as socially constructed, could open the door to more autonomy, credibility, self-determination, and access to basic human rights for people seeking support services for these impairments.

The literature review that follows defines and critiques the prevailing theoretical models that frame this project, explores some of the policy considerations that have

coincided with the paradigm shift from medical to recovery approaches and discusses recent work in the area of disability and mad studies. An emancipatory research approach is proposed and discussed as its tenants fit well with the overall goal of this research project of fostering self-determination for people with psychiatric disabilities.

#### A. **Conceptual Framework**

Under the traditional approach to psychiatry, crisis intervention and private payment for mental health disorders are influenced by the concepts of pathology reduction and safety management. In a system framed by the medical model the right to choose, or refuse, services in treatment is generally considered a privilege that is earned (Cook & Jonikas, 2002). The powerful influence of the medical model of care is visible even in community-based programs designed to provide support in the least restrictive way. Although the services in these settings are theoretically optional, services users come to community-based mental health programs from institutions through a referral which includes a diagnosis that qualifies them for services. The referral and/or the community mental health assessment results in list of Medicaid and Medicare approved supports that expert providers identify as necessary to keep that member safe and successful in the community (Fisher & Ahem, 2000; National Alliance for Mental Illness, 2007). In many cases the service user cannot be discharged from an institution if they don't agree to use the services provided by the community (Morris et al., 2014). Once services are put in place users must opt out of any they don't want. To opt out they are often required to prove they can manage without support (Cook & Jonikas, 2002). Having access and control over decisions, money, medications, transportation, and a final say in what services a user can opt out of means the balance of power lies with the



provider. In institutions, service users have been the recipients of lawfully supported forms of intervention in which providers strip people of their rights due to a perceived threat to themselves or others. The evidence indicates there are no positive impacts when the person's rights are restricted. In fact there are several negative outcomes including lowering people's sense of efficacy and creating a system in which those who need assistance avoid asking for help until their situation deteriorates significantly (Cook & Jonikas, 2002; Shimrat, 1998).

The literature around psychiatry is full of studies exploring lack of adherence with recommended treatments and interventions (van Dulman, Suijs, Dijk, de Ridder, Heerdink, & Besing, 2007). Davidson, Flanagan, Roe, and Styron (2006), point out why this line of thinking is ineffective, "...we contend that mental health care has failed to appreciate fully the fact that human beings function as active agents shaping their own lives and contexts at the same time that they are being shaped by their experiences and environments" (Davidson et al., p. 1142). The authors go on to argue that even though people with psychiatric disability often appear to lack motivation, they are always in motion trying to change their situation and move forward with their lives toward their interests and goals. In this pursuit they only seek help when they experience obstacles in their path or when they must engage with others in order to meet those goals. This is one explanation for why so often people, or groups of people, do not make changes based on the beliefs of others, even those in power.

1. **Barriers to human rights and power in people's lives**

In the 1980's psychiatric survivors were paying attention to the independent living movement that was in full swing for people with physical and sensory disabilities and began to demand their human and civil rights as people with disabilities rather than mentally ill patients (Deegan, 1992). Achieving human and civil rights for people with disabilities would mean they would have access to such things as privacy, opportunity to live their lives and work in places they want, and control over their personal decisions and decisions about services. To achieve basic human and civil rights, people with disabilities require that society reduce the physical or societal barriers or put continuously available supports in place that equal the playing field thus opening the door for them to have lives and work where they want - despite impairment. These supports allow for self-determination without the requirement of normality or near normality (Quinn & Degener, 2002). One outcome of the civil rights movement for people with psychiatric disabilities was the inclusion of their voices in policy decisions around psychiatric services.

2. **Self-Determination: Consumers Find Their Voice**

In January of 2000 the National Council on Disability (NCD) released a report titled "From Privileges to Rights: People Labeled with Psychiatric Disability Speak for Themselves." For the first time, in all the years of policy making regarding mental health services, the council elicited input from people with psychiatric disabilities. The report, combined with a growing body of research on recovery from severe mental illness, helped prompt the release of the President's New Freedom Commission Report in 2003 (Andresen, Oades & Caputi, 2003; Bellack, 2006; Davidson, 2003). The result of

the commission report is a vision that makes recovery the goal of treatment and lays out an expectation for a provider/recipient partnership in which the people with psychiatric disability choose "...who, what and how care will be provided" and have "... the option to agree or disagree with the treatment plan" (President's New Freedom Commission, 2003, p. 6).

### 3. **A shift in the power structure**

Mental health services users are starting to explore the idea of civil rights because of relatively recent disability rights laws. In addition, survivors and marginalized groups are starting to build connections through the internet resulting in a grass roots movement not unlike the one that resulted in the NCD (Quart, 2013). Since the New Freedom report was released in 2003 many states in the US have adopted a recovery based approach to mental health care, an approach that has come out of the consumer movement. On the insistence of people with psychiatric disabilities, community based programs must include peers on their boards as well as have trained peer providers in their services and as leaders in the community drop in centers. There are programs for training and certifying peer mentors to provide services such as Wellness Recovery Action Plans (WRAP) plans (Copeland, n.d.) as well as community transition and support services. Research in mental health intervention has shown that peer support based interventions have good evidence for effectiveness (Davidson, et al., 2001), and self-help groups have a key role in empowering people to take responsibility and drive their recovery process (Pickett et al., 2012). There are several political reasons for this shift.

#### 4. **Policy analysis and impact on Services**

Title II of the American with Disabilities Act (ADA, 1990) states that people have a right to be integrated into mainstream society; that although separate services for people with disabilities are okay, people have a right to choose to work and live everyday using the same resources and opportunities as those without disabilities. In 1999, the Olmstead decision in Georgia stated that forcing people to live in nursing homes and other residential living facilities against their will was a violation of Title II of the ADA (*Olmstead v. L.C.*, 1999). Despite the laws many states continue to use institutions to manage care for people with psychiatric impairments. The state of Illinois provides a good example of this challenge. In December of 2011, over 100,000 people with disabilities in Illinois lived in nursing homes, 15,000 of which were people with psychiatric disabilities (Illinois Department of Human Services [IDHS], n.d; UIC College of Nursing, 2012;). There are several kinds of institutions dedicated to the care of people with psychiatric impairments. In addition to regular nursing homes that house older adults as well as people with physical disability, and small private hospitals with psychiatry units, people with psychiatric disability are institutionalized in facilities called Institutes for Mental Diseases (IMD). States, by law, are responsible for the care of people with psychiatric disability and must pay for services provided to this population through a combination of state and matching federal Medicaid funds (Koyanagi, 2007). IMDs are defined by Medicaid as facilities with 16 or more persons of which half or more have diseases of the brain (IDHS, n.d.). In Illinois, the IMD's collect payment by taking the SSI and SSDI income of each person residing there, less a \$30 monthly allowance. The remaining cost for the care of these individuals in these settings is billed to the state because the IMD exclusion prohibits

these facilities from taking advantage of the matching Medicaid funds. In an article written for the Associated Press in 2010 Carla Johnson states that because IMDs do not qualify for the Medicaid matching funds, the state spends twice the amount it would on community care that would qualify for the Medicaid match. In 2009 Illinois taxpayers paid \$122 million dollars on care for people in IMDs (Johnson, 2010).

In September of 2010, Illinois settled a class action lawsuit referred to as *Williams vs. Quinn* (IDHS, 2011). Although this review considers Illinois, there are a number of states that have settled consent decrees, like the Williams decree (United States Department of Justice, n.d.). The Williams Consent Decree requires the state of Illinois to recognize the Olmstead Decision that upheld the rights of people with psychiatric disabilities to live and participate in the community of their choice. According to the decree Illinois' use of IMDs (mostly nursing homes dedicated to this population) to house people with psychiatric disability was found to be in violation of Title II of the American with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act because it "needlessly segregates" people and denies them the opportunity to receive services in a more integrated setting (IDHS-DMH, 2011, p. 1). The Williams decree requires that the state expand current community-based services to support the needs of qualified people with psychiatric disabilities who choose to leave the institution and live in the community. It also calls for community-based supports and services that are individualized and person-centered, and that support a plan created by a team that includes the individual. As a result of the William's decree (and other similar consent decrees focused on moving people with disabilities out of institutions in Illinois), the state of Illinois was forced to create a state-wide initiative to rebalance the money they spend on nursing home and IMD services,

shifting resources toward increasing community-based supports and services (Illinois DHS, 2011).

In 2011 the state created a transition plan designed to increase the number of people with psychiatric disability that it transitions to community-based services each year. The plan includes a description of the fundamental services needed in the community such as peer support services, recovery drop-in centers, as well as the services required to support successful transition (IDHS-DMH, 2011). The state has contracts with several community-based mental health programs, including Thresholds, to provide the identified support services and to help people with psychiatric disabilities navigate the system and transition out into the community. With support from these programs the state set a goal of transitioning 4500 people out of IMDs over the initial five-year period (2011 to 2016) established by the Williams decree (The University of Illinois College of Nursing, 2013). The *Williams vs Rauner* (formally *Williams vs Quinn*) Interim Court Monitor Report completed by Jones in June 2017, points out that December 2016 marked the end of the sixth year. According to the report as of December the state has successfully assessed and approved transitional services for 4014 class members. Of the 4014 approved only 1,923 have successfully moved with another 859 members somewhere in the process, many of which have been in the transition pipeline for an extended period (Jones, 2017, p. 7). The report identifies several reasons for the state's failure to transition the remaining 1733 that were approved. Six hundred and sixty-seven people refused to complete the transition after initially agreeing, and an additional 665 people were discharged from the nursing homes and are no longer accessible. Others have been identified as experiencing active psychiatric or medical symptoms that

preclude transition (222) or have been deemed “unable to serve” (303) (Jones, 2017, p.7). According to the report the state continues its efforts to create the needed supports for this class of people specifically working on plans to address the needs of those with more complex psychiatric and health issues in the community. One option on the table is an Illinois application for an 1115 Medicaid waiver plan that will help to create medical homes, and other evidence based interventions shown to provide support for more complex health needs. The 1115 waiver is a contract between a state and the federal government that allows the state to waive Medicaid requirements so they can pilot health policy initiatives they feel would better meet the health needs of their residents (Illinois Department of Healthcare and Family Services, n.d.).

Although inadequate services for complex needs is a major problem, the court report also addresses other confounding issues that are impeding the effort to rebalance the money from institutions to community services. One of the most problematic is the lack of low income housing that can be used in supported housing programs for people identified with psychiatric disabilities. In addition, despite the evidence that current community-based services are helping people live successfully in the community (less than 10% have moved back to institutions and greater than 90% express satisfaction with community living) there are still people being placed into nursing homes without being offered the option. Recent attempts to curb this practice in Illinois have had little impact (Jones, 2017).

## B. Definitions and Critiques of the Primary Theoretical Models

### 1. The medical model

Despite the growing focus on the Recovery Process Model in community-based mental health, the medical model remains the primary framework for understanding psychiatric disability in the helping system and in society as a whole. The term most often used for the array of psychiatric disabilities with highly variable symptomology is “mental illness.” According to Foucault (1976) until the arrival of the “*calm, objective* (emphasis added), medical gaze of modern medicine” in the late 19<sup>th</sup> century, madness was considered spiritual possession, sometimes even a spiritual gift (p.107). Since enlightenment, the medical model has viewed disability as the result of an underlying physical or psychological impairment due to a biological disease or injury.

In this model, it is understood that the impairment resides in, and is the direct responsibility of the person. Intervention is devised by expert providers with the goal of achieving a cure, or if not a cure, to control symptoms enough to achieve a level of normalcy that allows for effective participation in social institutions (Llewellyn & Hogan, 2000). Experts of illness or injury use measures with normative standards and classification systems to ascertain the existence and level of impairment (American Psychiatric Association, 2013; WHO, 2011). The determination of “symptoms” in the medical model are based on a “normal” that is often determined by consensus as with the Diagnostic and Statistical Manual which was created by teams of providers considered experts (American Psychiatric Association, 2013). Although the medical model is ground in evidence based practice the outcomes that are considered indicative of successful therapy are reductionistic, such as elimination of symptoms, or observable behaviors like



treatment compliance or acceptable interaction with others. The medical model assumes that participation in life resumes after symptoms are reduced or eliminated.

## 2. **The recovery process model**

People with psychiatric disabilities who felt the medical model did not reflect their lived experiences of recovery first proposed the Recovery Model. The model was a grass roots attempt to regain a sense of self-determination and hope that they felt had been taken away by the medical model's focus on illness and expert knowledge. The Recovery Process Model has evolved over time, primarily through the analysis of narrative stories and phenomenological research (Davidson, Sell, Sangster, & O'Connell, 2005). The body of research amassed on The Recovery Model between the late 1990's and today, reveals that recovery is not an outcome but a process in which people experience non-linear stages of recovery (Davidson & Roe, 2007, Andresen, Oades & Caputi, 2003).

This model is made up of many individual principles that are used to guide the development and provision of services in both private and public mental health care. The principles identified in the Working Definition of Recovery Model by the Substance Abuse and Mental Health Services Administration (SAMSHA) include hope and being treated with respect as well as support from peers and allies through relationships and social networks that are culturally based. Recovery is also person-driven, holistic, trauma informed, involves the individual with family, friends and community and in the end, occurs through multiple pathways (SAMSHA, 2012). Services that embody this process model recognize the importance of shifting decision-making power to the service user

within the helping relationship, and respecting their expert understanding of their own bodies and experiences in their lives and their symptoms (SAMHSA, 2012).

Davidson (2003) in his book “Living Outside Mental Illness” describes the results obtained when his research team analyzed over 100 in-depth qualitative interviews with people who have schizophrenia collected through a series of phenomenological research projects. Davidson identifies several important themes that inform the creation of a Recovery Process Model. According to the author, there are prevalent assumptions, such as the assumption that people with schizophrenia will not recover, that have been perpetuated by the lack of input from people with psychiatric disabilities. Participants identify lack of inclusion and lack of effort by professionals to obtain the information necessary for a holistic approach as reason for the poor outcomes of mental health intervention. Additional themes gleaned from this body of narrative stories include: having someone to rely on throughout the person’s recovery process; developing friendships that allow for give and take within the relationship rather than always being on the receiving end; having the supports and connections in the community to meet various social support needs; being able to successfully do things that are meaningful and important such as work, help others, volunteer, or care for their home; the need to deal with stigma and rejection that leads to inertia; fear of making mistakes; and finding the coping skills to manage the consequences of their diagnosis. Davidson stresses the point that social isolation, lack of inertia and loss of hope are far more likely to be the result of a combination of daily struggles with disruptive symptoms and the social and economic consequences of the disorder than an indicator of illness (Davidson, 2003).

Andresen, Oades, and Caputi (2003) completed a systematic review of the published experiential accounts of recovery with the goal to create a definition and a conceptual model for research and application. The authors identify four components of recovery: finding hope; re-establishing identity; finding meaning in life; and taking responsibility. The authors also identified five stages of recovery: moratorium, awareness, preparation, rebuilding, and growth. Moratorium is the stage of withdrawal and confusion after diagnosis. Awareness is a stage where people begin to accept their diagnosis, realize it can be managed, begin to take tentative steps and try new things. Preparation is a stage characterized by the person making the decision to work toward recovery and creating a plan. Rebuilding includes the hard work involved with engaging in activities that lead to re-establishing an identity. Growth is cultivating resilience and incorporating the components of identity and illness management into their day-to-day activities.

Bellak (2006) argues that the nature of Recovery, as a lifelong journey with an infinite combination of variables leading to success, does not lend itself easily to experimental outcomes research design. The theoretic understanding that recovery is a process implies that nearly everyone with a psychiatric disability is at some point in his or her recovery, making it difficult to establish systematic data on rates of and contributors to recovery. According to the author establishing supporting evidence for its use in mental health service systems requires a different approach, one in which support is established for each of the concepts identified in the process model.

Several studies do show support for the belief that recovery is non-linear and for the importance of hope when someone diagnosed with a psychiatric disability. Survivor

spokesperson Patricia Deegan (1996) identifies hope as one of the most important components in a person's recovery, in part because of a century long tendency for providers to discourage hope. Deegan's account, like the accounts of many survivors, highlights the tendency of her providers to discourage hope when giving her the diagnosis of schizophrenia. Deegan describes a period when she withdrew from friends and family as a protective coping mechanism from the sense of hopelessness that descended on her. She credits her family for her success in obtaining a PhD in psychology, stating that by because they never gave up on her she was able to regain her sense of hope and eventually redefine herself (Deegan, 1996). Anthony (1993) completed a review of consumer narratives of their recovery experience and like Deegan many described recovery as a non-linear process. According to Anthony people find themselves in a position where they need to recover not only from the impairment, but also from the social, emotional, and economic consequences of the disorder that discourage hope for recovery (Anthony, 1993). Davidson, Sells, Sangster, and O'Connell (2005), in an article focused on narratives of recovery, find support for the importance of establishing hope and having support from others. Participants also identified the importance of having the time and opportunity to redefine themselves as a person living with disability. According to the researchers, this was only achieved when they were able to engage in meaningful activities, resume responsibility and control and exercise citizenship while learning to manage symptoms. Another article by Onken, Craig, Ridgway, Ralph, and Cook (2007), identifies a body of research supporting aspects of the recovery process model from an ecological perspective. The authors contend that the person is in a relationship with the environment and recovery must take place within that context. The review covers a

combination of qualitative and semi-experimental research for the concepts of hope, sense of agency, self-determination, meaning and purpose, awareness of potentiality, re-authoring elements of recovery, coping, healing, wellness, thriving, power, social functioning and social roles, relationships, integration, and realizing recovery. The authors conclude that people draw on their internal and external resources and work at their own pace as they move through and between the different elements of recovery. This process requires navigating the challenges imposed by their condition in conjunction with societal inequality (Onken, Craig, Ridgway, Ralph, & Cook, 2007).

Recently there have been some important critiques from the disability community around the concepts of Recovery and the co-opting of the Recovery Model as an extension of a neoliberal agenda inherent in psychiatry and medicine. Walker (2006) argues that although Recovery began as something more complex, where power was in the hands of the person in recovery and the process was done outside of the medical arena, the incorporation of Recovery into provider services, or medicalizing recovery, has had the contrary effect of keeping power in the hands of providers. According to Walker, Recovery Model practitioners continue to use the vocabulary from medical and psychological models – words like mental illness, symptoms, overcoming, condition, managing triggers and illness management. In addition, the recovery model interventions used most often in provider based programs focus on the individual's responsibility to apply their strategies and stay on their personal recovery journey, without any focus on the social determinants of disability (Walker, 2006).

Morrow (2013) explores how the Recovery Model has taken on different meaning over time. Early on the survivor network touted the evidence showing potential

for recovery in order to challenge the medicalization and power structure of psychiatry. According to Morrow the professional providers' network saw the value in the language, usurped the term recovery, and redefined it to meet their needs. Morrow points out that the concept of recovery evolved in the early 80s and yet it took many years for the idea to catch on, in part because of the myriad ways that it was defined. The Toronto-based Mental Health "Recovery" Study Working Group (2009, as cited in Morrow, 2013), researched how survivors understood the concept of recovery. Their results indicated there were three different interpretations within this group: 1) Recovery as a personal journey; 2) Recovery as a social process that considers access to jobs, income, safety, housing, etc; and 3) Recovery as a critical reproach to the necessity of medical intervention to reduce psychiatric disability. The author argues that when state mental health authorities began to claim Recovery as their overarching model for services they did so from a neoliberal perspective. Neoliberalism is a discourse used in capitalism and medicine that promotes individualistic understandings of complex social problems. In other words, Recovery was used as another way to hold people responsible for their recovery while ignoring the social issues that continue to negatively impact mental health and inclusion. If recovery is considered a person journey, it will be difficult to broaden services and redistribute power in a neoliberal mental health system (Morrow, 2013).

### 3. **Self-determination theory**

At the heart of the Recovery Process Model is the value of fostering self-determination and choice for people with psychiatric disabilities. Corrigan et. al. (2012) identify self-determination as an "ethical manifesto" (p. 170). The authors contend that being human essentially means people have the right to choose where they want to live

and work, who they want to spend time with, and how they wish to express their humanity through such things as recreation, spirituality, and goal setting. It would be reasonable to assume that applies to the right to make personal choices when it comes to obtaining services related to physical and mental wellness.

Self-determination theory (SDT) builds on the basic concepts of the positive psychology movement that is focused on human strength and positive outcomes (Seligman & Csikszentmihalyi, 2000). The theory begins with three philosophical assumptions: The first is that people are inherently proactive in their lives rather than being controlled by internal forces, (emotional responses), or external forces (environmental influences). The second is that humans are self-organizing systems that strive for growth, development and integrated functioning. The third is that in order for people to function optimally there has to be opportunity within their environment (Seligman & Csikszentmihalyi, 2000). When people are denied opportunity to act, their growth-orientation is thwarted. There are several examples of how opportunity for people with psychiatric disabilities is thwarted. Most people who are diagnosed with serious psychiatric disability have experienced at least one traumatic situation in their past or as a result of their impairment. Also, people diagnosed with serious disability live in marginalized spaces because they are “different” or it is assumed they lack insight, lack credibility or are incapable of making good decisions. According to SDT an environment that does not allow people to meet their basic psychological needs will thwart the ability to learn and grow from their decisions and keep them from gaining optimal functional skills (Deci & Ryan, 2002).

Deci and Ryan (2002) state that there are three basic psychological needs that contribute to being proactive and self-organizing. These include the need for competence, the need for relatedness, and the need for autonomy. The need for competence refers to the person's desire to be effective when interacting and functioning within their environment. The care models that allow for self-determination begin with the assumption that care is provided in the community where people live and interact. Engaging in a process of trial and error and building on success allows people to become effective and confident rather than feeling as if they will never be able to meet the medical model requirements of normality. Recovery oriented providers can provide opportunity for reciprocal relationships and reflective feedback which also supports development of competence. Research on competence indicates that it is a necessary aspect of intrinsic motivation because having greater sense of competence is equated with a higher degree of identification with the task that needs to be done. For example, identifying with the role of advocate for disability rights is partly contingent on the person feeling they are competent in the skills required for that role. Identification is equated with greater happiness and well-being (Koestner & Losier, 2002).

The need for relatedness refers to a universal tendency to connect and interact and care for others (Deci & Ryan, 2002). According to Deci and Ryan relatedness is an important aspect of both extrinsic motivation and intrinsic motivation. For example, people will often do an undesirable task, such as test taking, because they have an important connection with someone who values that task, or they see it as a means to maintain or improve an important relationship.



A study by Davidson et al., (2001), demonstrates this concept. The researchers matched people with severe psychiatric disability who were in marginalized social positions with a volunteer who served as a friend. The pairs were provided with a small stipend to engage in activities monthly. All the participants in the study developed friendships with their assigned partner. The partner with disability increased their overall participation in community activities and developed a broader friendship circle as a result of the connections they made with their study partners. Although not researched as much as competence and autonomy, the evidence indicates that relatedness has an important role with the regulatory aspects of external motivation in the SDT theory, when a task or activity is considered necessary but is not gratifying in itself (Kostner & Losier, 2002).

The need for autonomy refers to the person's innate desire to interact with the environment (Deci & Ryan, 2002). In autonomous interactions, the person reflects on the situation and adjusts their actions in accordance with their values and interests so as to be optimally effective. According to Deci and Ryan (2002), autonomy is not about independence but rather having the willingness and the sense to act. Research on autonomy has shown that people who are extrinsically motivated to engage in tasks that are of value to them are likely to discontinue those tasks when that extrinsic motivation is removed. Those who engage without any extrinsic reward often continue engagement on their own (Deci & Ryan, 2002).

There is a large body of research to support the theory of motivation and the role of the basic needs of autonomy, competence and relatedness in the Handbook of Self-Determination of Research (Deci & Ryan, 2002). A summary of the research addressing motivation to engage in health and wellness activities is included here as it is of most

interest to this study. Williams (2002) considers a body of research addressing the implementation of wellness recommendations such as smoking cessation, weight loss, and abstinence from alcohol and medication adherence. Many of these studies included in the Williams review also inquired about how the person felt regarding their physician's support for autonomy when interacting. The author is careful to distinguish autonomy from independence, stating that autonomy means to willingly engage in behavior rather than to act alone as in independence. According to the author that means providers do not abandon the person in their decision but rather engage in behaviors that support autonomy (Williams, 2002). The research indicates that people are most autonomous when providers are sensitive to how much support a person wants as they make decisions and act on the environment. Supporting autonomy means providing access to meaningful choice, encouraging self-initiation and acknowledging the person's perspectives (Williams, 2002, Silva, Marques & Teixeira, 2014). All the studies in the review on health care prevention indicate that people, including people with psychiatric disabilities, are motivated to engage in behaviors when motivation is primarily autonomous. When they engaged in those behaviors people showed significant improvement in health and well-being. On the reverse side when providers pressure people to think, feel or behave in specific ways, people were much less likely to engage in health promoting behaviors (Williams, 2002).

Self-determination is a key aspect of the Recovery Process Model, yet the continued prevalence of the medical model, even in community-based programs, creates a barrier for people trying to be self-determined. Research is needed to determine how the

provider system can help improve access to autonomy and self-determination for people with psychiatric disabilities.

### C. **Impact of Institutional Living and Transitional Barriers**

A complex understanding of psychiatric disabilities requires exploring the impact of institutionalization and the current barriers to transition. Institutions are defined by the policies that control and fund their use. There are several different definitions of institution. For example, Medicaid defines institutions as facilities that assume total care of individuals for 24 hours a day (Medicaid.gov., n.d.). Definitions that guide policy decisions often include a required minimum number of inhabitants to be considered an institution. In the state of Illinois, a facility is identified as an institution when there are more than 16 individuals living together who did not choose to do so (IDHS, n.d.). Regardless of size there are documented consequences of institutional living, particularly if it is for a long period of time.

#### 1. **Institutionalization**

Chow and Priebe (2013) reviewed the literature that was published starting in 1961, the year that Goffman's book *Asylum* was published critiquing institutions for people with psychiatric disabilities, up to the year 2012. Their review considered how people adapted to long-term stays in hospitals or other institutions and the implications for their lives after discharge from these settings. The researchers use the term "Institutionalism" to describe a set of maladaptive behaviors they believe are induced by the tensions of institutional living. One study noted that people who lived in settings with few activities and little access to the outside, tend to experience the most distress from

psychological symptoms (Wing, & Brown, 1970). Several studies indicated that people living in institutions for long periods tend to lose their sense of independence (Liberakis, 1981; Wing, & Brown, 1970). Consequently, they tend to take little responsibility for independent living tasks and struggle with decision making resulting in failure to manage daily life activities when they transition out. Institutions rarely provide opportunities to learn adaptive skills related to social interaction so when people are released from these facilities they have difficulty interacting with people in society, or engaging in positions such as work or friendships that required social interaction (Liberakis, 1981). As a result, they remain isolated and on the margins of the community. Other studies indicate that people feel depersonalized and experience a loss of identity due to humiliating admissions processes in which their personal experiences are classified and labeled as disease (Goffman, 196; Rosenhan, 1973). In addition, people are forced to take on the burden of stigma. One of the studies included in the review categorized the loss of role participation, such as worker or family member roles, as a loss of identity (Gruenberg, 1967). Coupled with a significant increase in time spent in psychiatric intervention services and people eventually take on a sick “patient” role as their primary identity. Chow and Priebe (2013) note that cognitive capacity is not impacted by long periods of institutionalization and a small number of people saw their period of institutionalization as an opportunity for positive growth. The authors conclude, however, that many of the behaviors associated with “illness” are actually coping strategies and adaptations associated with institutional living (Chow & Priebe, 2013).

## 2. **Barriers to community transition**

The literature on psychiatric disability alludes to numerous barriers to community transition and living. The state of Illinois had been under a consent decree for the last 6 years and must produce bi-annual reports charting the state's progress in moving people with psychiatric disabilities out of the institutions. These reports, which are available to the public, provide a real life, contextual record of the barriers people with psychiatric disabilities face when trying to live in the community. One striking detail is the high number of people who are refusing to transition after being approved to enter the community-based programs. One potential explanation is that these people are struggling with the outcomes of institutionalism that Chow and Priebe (2013) identify. Illinois is also struggling to put community-based services into place that meet everyone's needs, in particular services that mitigate risk without taking away self-determination. This is particularly challenging for the 500+ people in Illinois who are considered medically complex or "unable to serve." According to the report occupational therapists in the state evaluated 39 people, all considered "unable to serve" with current services, and identified interventions that would improve the success of this group, however the state has yet to provide these services – in part because they include personal assistant services, an intervention that is deemed expensive and doesn't fit with traditional psychiatric services (Jones, 2017). The June 2017 interim report identifies several solutions to address this population. However, one of the options identified for those considered medically complex was transfer to a skilled nursing facility which is simply another form of institutionalization. Lack of access to affordable and accessible housing in safe areas of the city, areas that also offer access to resources such as grocery

stores, transportation and health services, is another barrier noted in the Williams reports. Recently Illinois put new initiatives in place to address the housing shortage, including additional monetary incentives for building accessible and affordable housing as well as training for landlords, but progress has been slow (Jones, 2017). Lastly the state identifies co-morbid medical illness as a primary challenge to transition. The average person coming out of the nursing home has 4-5 co-morbid health conditions that must be managed by the person once they are out of the facility. Funding was made available to increase and improve integrated behavioral and physical health programs however people whose medical conditions been created by, and then managed in institutions do not develop the skill or decision-making capacity, nor do they have the funding to make significant changes to their diets, engage in exercise programs or manage the transportation time and effort required for health promoting tasks (Chow & Prieb, 2013; Jones, 2017).

#### D. **Interventions Designed to Shift Power**

Community mental health programs identify self-determination and the principles of the Recovery Process Model as important aspects of success for community tenancy. Since the Recovery Process Model became the guiding framework for many mental health services there have been a number of programs developed that were intended to help shift decision making and power to the service users in the system. Many of these programs show positive outcomes. A critical look at these programs however, indicates that the positive outcomes indicated by the research do not reflect an actual shift in power. The review that follows is not an exhaustive list of these programs. That list is available in the Evidence-Based Practice (EBP) section of the Substance Abuse and

Mental Health Services Administration (SAHMSA) website. This review includes some of the more well-known and utilized Evidence-Based Practices (EBP).

1. **Assertive Community Treatment (ACT)**

ACT teams were developed to provide community support to people with persistent psychiatric disabilities who the greatest needs. ACT teams are made up of medical staff as well as community support, substance abuse and supported employment staff and are designed to be provide for all anticipated medical, work and daily living needs. ACT teams are successful in helping people set up and maintain an apartment, budget for and purchase food and necessities, obtain needed disability benefits, link people to supported employment and manage health needs including managing conditions such as diabetes or heart disease, making and keeping appointments and taking medication correctly (Fisher & Ahem, 2000; NAMI, 2007). Although these teams are set up to provide for a wide range of health and daily living needs, there are important limits to what they can do. ACT teams are required to bill an established number of hours for services. Billing is typically based on the number and type of contacts, not on the amount of time or quality of the contact (Illinois Department of Family Services (IDFS), 2014). Most teams are providing support for many different things, to many members – especially in states trying to meet quotas set in response to the consent decrees. Teams must provide all the tasks involved in the transition from institutions to the community, plus support a myriad of daily needs, all in the community where travel can add significant time between visits. That leaves little to no time to provide extra needed support for people who are learning money management skills or cooking techniques,

adapting cleaning tasks for accessibility, or developing the capacity to initiate valued leisure activities and build social capital.

## 2. **Peer Support Services**

An important aspect of the Recovery Process Model is access to Peer Support Services (PSS). Peer services, defined as services that are provided by a trained specialist who shares common life experiences with those they are serve, was born out of the belief that psychiatric survivors found healing and self-determination when they banded together to fight for their rights as part of the survivor movement (Cook & Jonikas, 2002; SAMSHA, 2010). The evidence for peer services is mixed albeit promising, depending on the goals and the outcomes identified as indicative of positive progress for people with psychiatric disabilities (Doughty & Tse, 2011). One critical review of research assessing the effectiveness of peer support services indicates that service users identify peer support services to be very helpful (Doughty & Tse, 2011; Lawn, Smith & Hunter, 2008). However, when peer support services were part of more traditional mental health provider program such as ACT the peer providers found it difficult to maintain the role of “peer,” functioning more like professional providers. On these teams, the addition of peer providers did not have an impact on the power relationship, leaving the power on the side of providers (Chinman, et al., 2014; Davidson, Chinman, Sells, & Rowe, 2006).

## 3. **Self-management and shared decision making**

Living Well (Goldberg et al., 2013) is a peer/professional delivered program designed for people with persistent psychiatric disability who are managing medical illness in addition to their psychiatric disability. The program uses several tools



including a personal health workbook, personal action plans with self-management goals created by the participants, peer communication regarding questions or support for plans, and a tool for communicating with their medical doctor. Participants meet to learn about medical conditions and the range of treatments and then are supported as they create their plans and negotiate treatment options with their doctors. A study by the authors indicates that participants are able to show improvement in their understanding of their condition and how it relates to their psychiatric disability. Results also indicate that participants are more active in the care of their medical condition, and meet goals related to their health behavior. Self-management plans that offer education, choice and supportive planning and tracking tools allow for shared-decision-making, trial and error and a method for tracking small successes. These tracking tools allow people to see their management successes and build on them even before the medical testing shows results (Goldberg et al., 2013).

Cook et al. (2012), completed a randomized controlled trial to determine the efficacy of the Wellness Recovery Action Plan (WRAP). WRAP is a peer provided program in which people with psychiatric disabilities create an action plan for their mental health care. Building a WRAP plan begins with creating a wellness toolbox, a resource list of effective self-care activities. The resources in the toolbox are then used to complete the five sections of the plan. The five components include: identifying a maintenance plan for daily coping; identifying emotional triggers; identifying early warning signs that indicate a potential crisis; identifying signs that indicate there is a need for a designated support person to step in and help; and an advanced directive to guide care providers toward preferred treatment choices in the event of a crisis. The WRAP

plan is created (and adapted as needed) when a person feels capable of making decision on their behalf and is based on experience, values and personal goals (Copeland, n.d.). Study results indicate that after participating in the creation of, and using a WRAP plan, people express greater hope and a higher sense of agency in their daily lives (see Cook et al., 2012). They also express feeling more comfortable about taking advantage of opportunities to acquire new skills, which in turn, improves their quality of life. Lastly they experience a significant improvement in symptom reduction (Cook et al., 2012).

Psychiatric advanced directives (PADs) are legal documents, prepared by competent people with psychiatric disabilities for future treatment during times when they are experiencing decisional incapacity (Swanson et al., 2008). PADs allow for decisions regarding which treatment options are preferred and which treatment options are refused. In addition, the PAD allows the person to assign a proxy decision maker to support the realization of their PAD during the crisis (Scheyett & Kim, 2007).

Proponents of PADs identify several benefits. First the very act of working with a provider to explore the treatment options and make decisions about what to include or not to include can foster an effective shared-decision-making relationship between the clinician and the person with a psychiatric disability. In addition, PADs allow the person to retain legal control over the decisions in their treatment, avoiding treatment that is against their wishes. The opportunity to assign a proxy decision maker provides additional support for making sure treatment matches what is indicated in the PAD.

Some PADs allow the proxy to sign for admission if necessary, thus avoiding an involuntary admission process. Aside from the emergency department staff, the PAD can provide communication to the police and transport people so they know how to be most

helpful in a crisis situation (Swanson et al, 2008). Research on PADs indicates that people who have used them have been able to avoid interventions that are against their will. They also experienced greater respect from providers during the crisis. PAD users state that overall they felt the PAD created better interpersonal interactions with providers than in previous crisis situations (Swanson et al., 2008).

Advocates for system change feel that recovery happens when people feel empowered. This means support programs must provide services that allow for self-determination and mitigated risk taking. According to Lunt (2004) the solution is providing people with choices that are meaningful. A meaningful choice means having the opportunity to choose between a variety of options, including options that fall outside the recommendations of providers. Shared decision-making is increasingly recognized as a valuable and effective process in mental health care (Drake, Cimpean, & Torrey, 2009). Shared decision-making requires the professional to recognize that decisions are made in relation to a person's goals and lifestyle preferences. Professionals who develop their knowledge of and access to a variety of alternatives can support decision-making through the presentation of real options. Respect for choice means respect for the right of the person to experience the consequences of whatever decision they make. Drake, Deegan, and Rapp (2010), suggest developing an electronic decision support system to connect the clinician's knowledge of effective treatment with the person's preferences. Programs like this can support fidelity in applying evidence supported treatment programs, increase knowledge and access to resources and help to assess the potential risks of each decision (Drake, Deegan, & Rapp, 2010). A meta-analysis of 13 studies on self-management programs completed in 2013 revealed that people who created and used intervention

plans through a shared decision-making process in a self-management program had significantly fewer re-hospitalizations for relapse, adhered more readily to a negotiated medication regimen, and showed significantly greater autonomy and responsibility in dealing with their psychiatric impairment (Zou et al., 2012). The self-management interventions that include education and share-decision making can shift the power in the intervention process to the person with psychiatric disability and allow them the ability to take risk with a non-coercive safety net. In addition, preliminary research indicates that self-management plans result in better outcomes in traditional indicators such as medicine adherence and hospitalizations, as well as in measures of autonomy, hope and quality of life (Zou et al., 2012).

One of the few programs in the literature where services users are given what appears to be complete control over determining their services is described by Cook, Russell, Grey, & Jonikas, (2008). The Self-Directed Care (SDC) model was a state implemented program in which service users could choose what services they would like to have. Those services were paid for using the money that would have normally been spent on their community mental health services and other medical interventions. In this program, the person still has the option to purchase some or all of their services from the community provider but they can also choose other activities or services in the community that they feel would be helpful, for example a restorative yoga class. The program includes a number of safeguards to minimize risk. According to the authors the initial pilot program appeared to be fiscally responsible and more effective for service users (Cook, Russell, Grey, & Jonikas, 2008).

Allowing for autonomy and self-determination is at the heart of the Recovery Process Model and at the heart of civil rights for people with psychiatric disability and the basis for the intervention programs just reviewed. Unfortunately, this may be the aspect of the model that will be most challenged, in part, because many mental health professionals even now embrace a medical model and/or believe that people with psychiatric disabilities do not have the ability to make their own decisions. All of the programs are designed to increase decision-making on the part of service users yet few shift power or lend credibility to people with psychiatric disabilities, largely because they focus on services and not on accessibility to civil and human rights or social participation. A recent article about an impending hurricane in Florida indicated that Miami officials planned to commit homeless people to institutions if they refused to evacuate, stating their refusal was an indication of mental illness or substance abuse, and by insinuation, an indication of poor judgement (Smiley, 2017). This was in stark contrast to the homeowners who were given the right to remain in their homes despite the potential risk of danger and need for costly rescue during the storm. Although every one of the interventions reviewed here are designed to increase access to self-determination, most continue to place the responsibility for recovery on the person and few consider the disabling impact of poverty, stigma, marginalization, and oppression that people with psychiatric disability experience every day.

The literature suggests that Recovery Process Model framework has led to evidence-based-practices that allow service users to have a say in their treatment plans and support services. However, there has been little impact on the social inclusion, particularly for those with significant impairment. It is worth researching the impact of

introducing disability and mad studies concepts into the discourse around disability, impairment and the expectations of the psychiatric community. This project is designed to explore if introducing these ideas to a small group of service users and providers could shift the power imbalance in the helping relationship, thereby opening doors to true self-determination.

#### E. **Critical Disability and Mad Studies**

“Some have argued that institutionalized discrimination against people with mental illness” is in fact “one of the last socially-acceptable, government-sanctioned threats to the rights of a large class of vulnerable individuals” in the United States (Cook, 2000, p. 199)

##### 1. **Disability challenges to the medical model**

Some disability scholars argue that medicalizing psychiatric disability has unintended consequences, or even that the medicalization of psychiatric disability is inappropriate (McGruder, 2002; Price, 2011).

The vocabulary of the medical and psychologic models inherently positions the clinician as expert interpreter of the client’s experience. Seemingly benign words like “clinical”, “treatment plan”, “case”, etc. also bring with them a context in which the client is seen as “abnormal” or having a “pathology” while the clinician has the role of performing ‘interventions’ or other activities to help the client overcome their “pathology.” The power of definition is in the hands of the clinician. Once labeled “abnormal” (aka “mentally ill”) you’ve been pushed to the

edges of society – where your views and concerns are considered not important (Walker, 2006, p.7)

McGruder (2002), and others, argue that the signs of psychosocial impairment are highly variable and do not lend themselves easily to establishing a demarcation point for normal v. abnormal (Corrigan, 2011; Davidson, 2002; McGruder, 2002). For example, McGruder (2002) argues that it is not reasonable to define spending money, an experience often associated with mania, as a symptom that results from too much or too little of a neurotransmitter without considering the importance of spending money in the current culture of consumerism. In a biomedical context, a “symptom” leads a person to seek help with the goal to eliminate that symptom in order to feel “normal.” According to the author however, spending money gives the person’s high mood a “normal” social meaning since purchasing goods is often an expression of love of self or part of a ritualized gift exchange in the culture. Identifying these actions, or even hallucinations and delusions, as symptoms assumes these experiences are simply unwanted, pathological indicators of impairment. Many people identify their experiences as an important part of who they are and feel that medicalization of their experiences negates the value of significant portions of their lives (McGruder, 2002).

Davidson (2002) in a discussion that considers several “symptoms” of schizophrenia illustrates the value in seeing these experiences as normal human reactions to a change in mental health status. The results of their analysis of over 100 narrative interviews with people who identified with schizophrenia, indicate that asocial behavior, avolition, anhedonia, and other “negative symptoms,” considered by medical professionals as the most debilitating biomedical markers of the schizophrenia, are more

often a natural reaction to the onset of the cognitive and perceptual changes, and more importantly, to the response of their friends, family, and the medical community (Davidson, 2002). Deegan (1996), in her essay on her personal recovery journey identifies that period of her life as serving an important purpose. She states she needed time to redefine who she was, to include her new disability experiences:

The fact that I was unmotivated was seen as a problem by the people who worked with me. But for me, giving up was not a problem, it was a solution. It was a solution because it protected me from wanting anything. If I didn't want anything, then it couldn't be taken away. If I didn't try, then I wouldn't have to undergo another failure. If I didn't care, then nothing could hurt me again. (Deegan, 1996, p.5)

A review of the recorded history about madness that spans centuries, indicates that disease specific diagnosis and intervention is a small part of the most recent history, one that coincides with the growth of the insurance and pharmaceutical industries (Price, 2011). The author points out that even today there are numerous definitions of madness including legal definitions, medical definitions, and definitions around magic, creativity, and spirituality. All the definitions, however, establish a demarcation point meant to highlight the difference between those with madness and those without, or normal and abnormal. What is important to note is much like intellectual and learning disabilities, the criteria for determining madness changes to reflect the most current ideology in society (Gillman, 2014).

Madness can be traced back to prehistoric times when mental illness was considered a supernatural phenomenon. In Ancient Greece, Galen wrote about the Theory of Humors



and the impact of excessive bodily fluids in one of the first accounts of madness as disease. For centuries before enlightenment madness fluctuated between being a disease of the mind requiring removal from society, or lunacy caused by spiritual possession or witch craft, or eventually a result of industrialization (Roberts, n.d.). In the early 1900s it was discovered the catatonic state referred to as General Paralysis of the Insane (GPI) was prevented when syphilis was cured with medications. GPI was rampant and rising in the asylums of the late 1800s. Many psychiatrists at the time noted the relationship to sexual excess, among other things. Some even characterized it as a disease of “civilization” blaming the growth of urban and industrial life (Wallis, 2012). After discovering bacteria and subsequently a cure for syphilis thereby preventing GPI, physicians and researchers began to redefine psychiatric disorders as medical illness and the search began for other biological causes and interventions. Several of these interventions reduced challenging symptoms and opened the door to community tenancy and better lives for people who would otherwise have been institutionalized. Yet many people feel the pendulum swung too far to the medical side. In the late 1800s the focus in medicine turned to preventing medical illnesses which included the use of eugenics. Sterilization of people with psychiatric disabilities, as a form of prevention, began in 1897 and continued until well into the 1970s (Gillman, 2014). Gillman (2014) asks the question what would be the impact on practitioners and people with psychiatric disabilities if societies understanding of these disorders changed “from medical illness to socially constructed disability?” The early responses of people living with psychiatric disabilities who have been introduced to this idea are mixed. Many express a strong desire to come out from under the oppressive umbrella of the powerful medical

community, yet people also wish to preserve their legal protections and their access to services that have been afforded with a diagnosis (Gillman, 2014).

## 2. **The hegemony of power**

Disability and Mad studies discourse explores the construction of disability and mental illness and the forces in psychiatry, in the medical community, and in society that establish and maintain psychiatric oppression (Diamond, 2013). Disability Studies literature often references Foucault's work on discourse, power and knowledge and discipline to help explain the marginalized positions of those with disabilities in society. Foucault defines discourse as "the group of statements that belong to a single system of formation." "Discursive formation" is when statements are grouped together, used, received, reused then re-grouped until they become general assumptions in society. Those assumptions are used to obtain desired outcomes or as elements of strategy (Price, 2011).

Price explores the subtle linguistic differences that impact the experiences of people with disability. For example, the term wheelchair user indicates that someone uses a chair for mobility but the term "wheelchair bound" leaves the impression the person is confined and worthy of pity. Price explores the powerful discourse around psychiatric disability that leads to societal tendencies to not only dismiss the thoughts and concerns of those with psychiatric impairment, but also leads to the belief that having a psychiatric disability means someone is a danger to society. Price (2011) argues that once a person is labeled with a psychiatric diagnosis they lose *rhetoricity*. According to Price, "rhetoric," defined in the Merriam-Webster dictionary as the art of speaking or writing effectively (Merriam-Webster, n.d.), is a pervasive endeavor that allows people to come across as

reliable, as making sense and/or as a likable and credible person. Rhetoricity allows a person to be received as a valid human subject and to lack rhetoricity is a form of oppression that takes away personal freedom and rights, including the freedom of expression and the right to be listened to (Prendergast, 2003). In her book, *Mad at School*, Price (2011) traces the rhetoric around well-known school shootings in the US, illustrating how powerful rhetoric from authority figures, the media and institutions in society, including academic institutions, highlight small details that draw on and then strengthen society's biases about the dangerousness of those with psychiatric labels, and ignore the more pressing issues related to the oppressive treatment of anyone who is different.

Much of Price's work focuses on institutions of higher education. In another book on disability and mad studies, *Mad Matters* (LeFrancios, Menzies, & Reaume, 2013), contributing authors look at several other sources of power that serve to oppress people with psychiatric disabilities. Diamond explores the anti-psychiatry community and the language that is a part of the member's identity and experience. Identity and experience based words like patient, ex-patient, psychiatric inpatient, used early in the anti-psychiatry movement, gave way to words like psychiatric inmate and ex-inmate. Later, words such as mad, psychiatric survivor and consumer took over. Diamond acknowledges there are benefits to using the word consumer rather than patient, yet the words consumer and even survivor have the same underlying tension in that they still establish a position in relation to the entrenched psychiatric institutions. Diamond argues that acceptance and understanding about the power of language in relation to social positions is one of the important struggles for the anti-psychiatry community, and maybe

in the larger disability community. Although many people with psychiatric disabilities accept the word consumer as someone who is in a position to choose services, others note that it gives the impression of freedom of choice and fails to communicate the actual experience of many, that of coercion and even violence in the treatment system. People who are comfortable with using the term consumer feel that the anti-psychiatry group is overly harsh in their criticism. Diamond contents that in the end this debate is serving most to divide people into different factions, effectively decreasing the grassroots movement toward real change in the system. Diamond states: “It is evident that awareness about marginality within community spaces varies a great deal among people and that sometimes a general lack of awareness allows for the reproduction of hegemonic power dynamics, even within spaces that are constructed to challenge the dominant social order (Diamond, 2013, pg. 71).

Rose (2016) explores the world of psychiatry as an industry ensconced in law. Rose points out that psychiatry is the only profession allowed to commit people to an institution when they have not committed a crime. Commitment is based on their identification of symptomology and resulting diagnosis of mental illness or disorder. Numerous critiques of this practice have gone unheeded because, according to Rose, they contain the words mental illness, disorder and symptoms in the critiques. According to the author any critique of the psychiatric system that uses this wording is ineffective because it continues to activate the hegemony of psychiatric power, regardless of intent. The author suggests terms she calls “refusal terms” such as “sense of well-being” rather than mental health or “way of being not seen as normal” rather than mental illness or disorder (Rose, 2016).

Chohen (2016) explores the power of expert knowledge and the limits of resistance in the face of this hegemonic belief. Chohen argues that resistance often takes the form of critiquing the system or of telling personal stories of living with psychiatric impairment. Attempts at resistance using these formats do not coincide with the bio medicalized understanding of disease and illness and as such have not changed the oppression experienced by psychiatric service users. According to Chohen psychiatric discourse reinforces the norms and values of a dominant social order that includes heteronormativity, gender inequalities and white supremacy. Chohen points out the latest edition of Diagnostic and Statistical Manual (DSM) is an example of the economic priorities of a neoliberal, capitalistic society focused on productivity and pathologizing undesired behavior. Chohen suggests that the focus for disability rights advocates needs to be less on getting psychiatry to give up its power and more on the social structures that sanction the expansion of knowledge and the power of expert psychiatry (Chohen, 2016).

### 3. **Madness, disability and impairment**

Attempts to de-medicalize psychiatric disorders are met with resistance from a number of different sources. A few of these areas of resistance have been address earlier in this review including the hegemonic psychiatric system that resists a change in power, the stigma that strips people of rhetoricity and the fear of losing ground around the tentative gains made toward obtaining disability, human and civil rights. The research and writing done by disability scholars has slowly started to shift the public's understanding of disability away from a medical problem toward providing support needed to realize their human rights (Oliver, 2013). As disability studies has moved toward a more social model approach to defining disability, however the inclusion of critical discussion about

psychiatric impairments is limited. Kalathil and Jones (2016) edited a special edition of *Philosophy, Psychiatry and Psychology* on the critical underpinnings of user/survivor research and co-production. According to the authors the call for papers revealed the fact that mad theory and user/survivor research is primarily Euro-American phenomena and in addition there are few established user/survivor researchers in the academy at all. Kalathil and Jones point out that this is for several reasons including a lack of funding for this research and a lack of mentoring and career development support for people with psychiatric disabilities wanting to become researchers in disability studies. In the end only those who are perceived as minimally mad or are mad in culturally acceptable ways are afforded access to academic supports for user/survivor research (Kalathil & Jones, 2016).

Jones and Brown (2014) set out to explore the impact of not including psychiatric disability discourse in the larger disability studies literature by reviewing recent disability studies articles. They identify three major consequences. The first consequence is that simplistic biomedical and genetic attributions of “mental illness” have led to an exacerbation of stigma. This is contrary to the beliefs of many, including service users and families in the system who thought that a public understanding of disorders as illness would decrease the shame surrounding “bad” behavior. The result however, was to increase the perception of seriousness, permanence, and dangerousness. Another consequence of not including psychiatrically disabled researchers is that those empowered to produce knowledge are those who treat abnormality or pathology. While the disability literature moves increasingly toward works around culture, art, identity, and theory the literature around psychiatric disability continues to focus more on treatment,

rehabilitation and recovery. Lastly, a clinical approach to disability lends credibility to the idea that only those with expert knowledge are able to “treat” or care for those with psychiatric disability. The result is increased isolation and a tendency to place little value in personal experience and the meaning of experiences. The language of clinical diagnosis and embraces the institutional approach that leads to identity as a chronic patient (Jones & Lewis Brown, 2014). The authors point out the greatest number of requests for disability services in academia are now coming from people with psychiatric disabilities. They note that the ADA does not afford clear protective rights. This and general attitudes in academia are impacting access to supports for both students and faculty and of course for academic researchers who identify with a psychiatric disability. The question of whether to include psychiatric disabilities in the greater disabilities discourse or to establish a separate discipline of Mad Studies is not resolved by these authors although they do state that inclusive disability language could address some of the issues around access to support for knowledge production in academia (Jones & Brown, 2013).

Several authors critically review the research knowledge that has been produced through collecting and analyzing narratives of lived experience of psychiatric disability. Much of the work that set the stage for the construction of the Recovery Model was produced through expert researcher analysis of personal narratives from people with psychiatric disability (Walker, 2006). Telling stories has been a hallmark of organizations who identify as advocates for people who have psychiatric disabilities. Voronka (2016) calls into question research that assumes people’s personal stories are indicative of the experience of everyone with a specific disability. Voronka’s argument explores work by

Joan W. Scott (1991) who states that bringing forth numerous subjugated stories, often stories of overcoming “illness” or disability, has served to multiply and complicate notions of psychiatric disability and may not be useful in challenging social justice issues. According to Voronka, personal histories tend to draw on the very power of orthodox history without challenging it, they never get to the root of “difference” and most importantly they reproduce rather than undercut the ideological systems in place. Voronka goes on to ask the reader to consider “what are the conditions of being recognized as a viable “lived experience” subject that is able to work in the mental health assemblages” (pg. 197). She points out that people who come from poverty or marginalized positions have a relatively insubstantial role in the production of knowledge (Voronka, 2016).

Writers in Mad Studies have begun to explore the social model of disability as an alternative to the medical model. Mulvany (2000) challenges sociology researchers to consider application of the social model as a research framework for research with people with psychiatric disability. Her argument identifies the value of refocusing research to include analysis of space, social barriers, rights of citizenship, and barriers to education, recreation and employment. Mulvany, in her review of the literature around disability studies and madness delves into the literature on impairment and on the concept of “difference”, pointing out the challenge of adopting this concept as a part of psychiatric disability. Mulvany points out that sociological research has not come to a conclusion, and even avoids the idea that a range of mental impairments result in psychic pain or impact the performance of activities. In an attempt to solve this issue Mulvany turns to disability theorists who write about the body as a corporeal and social construction,



arguing that the concern around the term impairment can be resolved through the recognition that what is and isn't normal is socially constructed (Mulvany, 2000). Mulvany states that most important is the idea that the experience of embodied impairment must be researched within the context of the disabling environments, something that has not typically been done in research on psychiatric disability.

Peter Beresford (2004) have written about and completed research around the social model of disability and the issue of impairment. Beresford considers a general social model approach to psychiatric disability research. Beresford explores the resistance found when psychiatric service users/survivors are encouraged to consider moving away from the language and approaches of the medical perspective of psychiatric disorder to that of the social model perspective and he identifies two reasons for the resistance. Beresford points out that after psychiatric service user/survivors are labeled with a diagnosis they struggle with being taken seriously so there is fear that rejecting an individualized, medical model approach would lead to simply being discounted as irrational. The second is a tendency for people with psychiatric disability to reject monolithic theoretical principles. Having been dominated by the medical approach, outspoken critics hesitate to consider another monolithic approach that could potentially preserve the current position of subordination. According to Beresford, the Recovery Model is being tied more and more to medicalization. He suggests that theorist consider a more rights based approach to disability identity arguing that the Social Model is a starting point for creating a new strategy (Beresford, 2004).

In 2010, Beresford, Nettle, and Perring completed a study exploring what service users thought about a social model of madness and distress. The study was a two-year

national project in the UK exploring the idea of a social model of madness and distress. Researchers wanted to engage people in a discussion about the social model of madness and distress, and to identify future areas of research and development. The research involved people with experience as mental health service users, people who experience physical impairment and disability and people who experienced physical disability and were also mental health service users. The authors explored a number of issues around the understanding of mental health challenges and came to several key conclusions. There was general agreement that the medical model has contributed to increasing stigma and that more social approaches support a broader interpretation of psychiatric disability. Most agreed that what is restricting and disabling are the social barriers and most agreed that there was potential for real gains for greater unity, shared identity, and more valued approaches to supports. At the same time there was ambivalence around terminology – some did not want to be labeled as disabled, a term they associated with a negative connotation, nor did they feel comfortable with the concept of impairment. Others did not see the model as helpful for this reason (Beresford, Nettle, & Perring, 2010).

Beresford and Russo (2016) explore the emergence of Mad Studies as an evolving area of Disability Studies since the book *Mad Matters* was published in Canada in 2014. The authors note that Mad Studies is not the first progressive development in the attempt to address the effects of the medical approach to psychiatric disability. The authors state that Recovery and Peer support are both identified as progressive efforts meant to challenge professional authority and highlight people's right to self-agency. However, they point out that both of these movements have been modified to fit a neoliberal agenda – recovery has been increasingly used to force people into employment and cut support,

and peer support has been used as a vehicle for restricting access to professional help, creating a low paid work force rather than recognizing the equal or greater value of peer intervention (Beresford & Russo, 2016). The authors concur with work by Mike Oliver (2013), in his critical look at the first 30 years of the Social Model, saying when critical discourse identifies problems without offering solutions it stymies progress for people with disabilities. Beresford and Russo challenge writers of Mad Studies to avoid this pitfall. They offer several strategies for supporting the success of Mad Studies as a discipline and for improving the potential for the Mad Studies research and discourse to change the status quo. Those strategies include locating Mad Studies research in user/survivor led organizations as well as challenging the divide that can grow between activism and theory building (ideas and practice). Mad Studies must place addressing diversity and privilege as a central aim. Work in Mad Studies must be participatory and inclusive, non-hierarchical and non-medicalized and it must seek to build alliances between professionals and service users (Beresford & Russo, 2016).

Oliver (1992) states “Changing the social relations of research production will, at least, offer the possibility of developing a social research enterprise which is relevant to, and significant in, the lives of those people who are the subjects of this enterprise” (p. 103). The act of completing research *with* people who have psychiatric disability, rather than *on* them, has a better chance of increasing their sense personal of self-determination and will hopefully change their lives for the better.

The literature indicates that people with psychiatric disabilities have grown increasingly wary of the medical model approach to psychiatric disabilities. Service users and researchers are gradually starting to explore alternative frameworks, such as the

social model of disability, but there is ambivalence about adopting terms that have historically been thought of as negative, or losing the ground they have made securing services and welfare benefits (Gillman, 2014). This project addresses the need for research that determines if introducing models of disability such as the Social Model, will result in a greater sense of empowerment in the psychiatric disability community as it has in other disability communities. The power held by psychiatry, to label the experiences, and define the lives of those with psychiatric disabilities need to be acknowledged. For that reason, this project will purposely introduce the concepts to a group that is made up of both service users and providers to see if participants recognize the power held by providers and the impact that has on access to self-determination for service users.

#### F. **Methodological Approaches**

People with psychiatric disability have mostly been subjects of research. People with psychiatric disability have also been subjugated in other ways – as the subject of horror films, news broadcasts, TV shows, and books (Schultz, 2007). In traditional medical model intervention programs, the people who continue to have symptoms despite medical intervention often find they are subjected to measures of control and containment (National Council on Disability [NCD], 2000). The combination of stigma and impairment focused intervention negatively impacts sense of power in decisions and daily life, and oppresses autonomy and self-determination (Ryan & Deci, 2006). One of the strongest arguments for using emancipatory research with marginalized populations such as this is the balance in the power relationship between the researchers and researched. Oliver (1997) defines emancipatory research as a paradigm in which knowledge is used to facilitate a process of confronting oppression. In emancipatory

research the power is shared between the researcher and those with disability as opposed to the traditional power relationship where the researcher makes decisions and forces the research process on the subject who has no say in the process or outcomes (Cornwall & Jewkes, 1995). The bulk of research related to mental illness and intervention has been done by non-disabled researchers on people with disabilities. Oliver (1992) explores this relationship stating that in traditional research the researchers hold the power. The researchers determine their research agenda and then personally benefit through publications and promotion. The research participants have little or no input into what is researched and rarely benefit personally from the results of the studies they participate in. Oliver suggests that the emancipatory approach requires the study participants become partners with researchers in deciding the research agenda, interpreting the results, and participating in decisions related to dissemination. An important aspect of emancipatory research is the understanding that results must have immediate benefit to the community of people participating in the research process (Oliver, 1992), but also that knowledge creation comes from experiential knowledge as well as scientific methods and theories.

1. **Participatory approaches to research**

According to Cornwall and Jewkes (1995), participatory methods fall under the emancipatory paradigm and work to pull people together who have a shared experience in their community. Community-Based Participatory research (CBPR) is not a method but a methodological approach for research production (Cornwall & Jewkes, 1995). Unlike conventional research that focuses on research for knowing (separate from implementation) participatory research is focused on “knowledge for action” and considers the specific priorities of the participants and communities in which it is

conducted (Cornwall & Jewkes, 1995). Participatory research can take different forms within a continuum, one such approach is Participatory Action Research (PAR). Drawing from Kurt Lewin's action research paradigm and Paulo Freire's critical consciousness approach to working with disenfranchised and marginalized groups, PAR participants work from an explicit political stance meant to empower the community to act and transform their life situations (Cornwall & Jewkes, 1995). Participatory methods give people with disabilities the opportunity to set the research agenda based on their research priorities, and enables them to find their own solutions to identified problems (Stringer, 2014).

CBPR can be led by people with disabilities or by researchers who contract with people with disabilities to contribute to portions of the research project. In many cases community-researchers are included on the primary research team, contributing to the identification of the research question all the way through the analysis of the results. University-researchers serve as consultants on the process and may have a hand in the acquisition of funding and the process of dissemination (Cornwall & Jewkes, 1995). A growing number of participatory action research projects show that joint efforts to identify and solve a problem can result in stronger outcomes both in research and in service provision, sustainability of efforts, and may be a model that changes the relationship between providers and users (Cornwall & Jewkes, 1995).

## 2. **Critical discussions of emancipatory approaches**

A small number of researchers who identify with a psychiatric disability have offered important criticism of qualitative approaches that utilize stories of lived experience. These critics point out that qualitative researchers who include narrative data

need to consider the position of power they hold in the process of collecting, combining and interpreting the narrative stories of participants. Russo (2016a) challenges her reader to consider the question; Are survivors' personal accounts their life stories or data for the researcher? Russo points out the ethical challenge of ownership of these narrative accounts. Although on the surface it would seem the stories are owned by the participants and the analysis by the researcher the whole situation is complicated by the power the researcher holds over how the stories are interpreted and used. This must be considered in context given most participants who are service users have already had their stories interpreted and classified in the process of receiving a psychiatric diagnosis. Russo (2016b) states that individual narratives are complex and the process of identifying a unified experience of madness ignores the many different ways in which people experience madness both internally and externally, and in context with other identities they may have (gender, age, etc). Russo asks that researchers consider how they will highlight all the factors that contribute to experiences rather than narrowing the analysis down one or two outcomes. According to Russo an intersectional analysis of factors that address the complexity of experience must direct the methodology and the chosen methodology needs to consider continuities between intersecting groups rather than differences (Russo, 2016b). A methodological approach that involves joint knowledge production is one option. This approach begins with collecting an oral history of each participant including the principle researcher's and then using those histories to inform the process of collecting and interpreting narratives of disability experience (Russo, 2016b).

### 3. **Disability studies and participatory action research**

A participatory action research (PAR) project that was done in the Tenderloin District of San Francisco illustrates how PAR research can be used to educate people about the societal structures that lead to oppression and marginalization, as well as to help them feel empowered to fight for changes in policy and services to improve their situation (Davidson, Flanagan, Roe, & Styron, 2006; Minkler, 1985). Working with older adults living in single room occupancy (SRO) housing, Minkler and her participants identified poor health, isolation and powerlessness as key challenges to daily living. After a period in which Minkler worked with the community to raise their consciousness about the community and policy based sources of their struggles she helped them start The Tenderloin Senior Outreach Project (TSOP) to address the problems. The project was designed to be an interactive program that incorporated PAR and self-help strategies focused on changing the community. Through the TSOP project, the participants brought in programs that increased nutritional awareness and improved resources for healthy food, improved safety through increased policing, created safe social venues for interaction and social support and lowered crime by 18%. The participants, who previously identified themselves as surviving day to day in isolation and fear, began to identify as part of a coalition, providing support to each other as they worked toward the shared goal of addressing and solving the problems in their community (Minkler, 1985).

de Wolf (2009) was asked to work with a local advocacy group that was concerned about the “not in my backyard” attitudes that were impacting development of supportive housing projects for people with mental illness who were seeking community



living opportunities. The advocacy group worked with de Wolf to identify the research question and methodology, obtain Institutional Review Board (IRB) approval, conduct interviews and analyze the results. The goal of the project was to develop a presentation for the community that successfully disseminated their findings related to property values and attitudes in neighborhoods that included supportive housing programs. In addition to a successful campaign that altered the attitudes of people in the neighborhoods slated for supportive housing programs, the PAR project effectively improved the self-efficacy of those who participated as community-researchers (de Wolf, 2009).

This finding was also illustrated in projects published by authors Schneider (2010) and Russo (2012). Schneider was a co-researcher on two PAR projects with a group of people who identify with psychiatric disability. The first was related to communication with psychiatrists and the other looked at housing for people with psychiatric disability. In Schneider's book *Hearing (our) Voices* (2010), the author uses diary entries to illustrate how the group increasingly felt empowered to live their lives and affect change in their situations through the PAR process. Russo (2012) describes two PAR projects with people with psychiatric disability that use a similar process. The first one is focused on homelessness for people with psychiatric disability; the second explores the implementation of "person-centered" care in mental health treatment programs. In both Schneider and Russo's projects, the researcher initiated the first PAR project, but the second project was initiated and completed by the newly empowered community-research group with the researcher as consultant. In both cases the process resulted in the community-researchers growing and pushing themselves to do things they thought they could not do prior to the projects. Both examples include a methodology for

collecting the thoughts of the community-researcher group as they progressed through the project stages (project conception, learning to interview and run focus groups, analyzing and disseminating the results). Russo identifies focus groups as a means of capturing the thoughts of the emerging researchers. Schneider employed the use of reflective journals. By including the journal entries from her community researchers throughout her book, she could illustrate the successful transformation of her community-researchers from service and research recipients to drivers of and active problem solvers in the PAR process.

PAR methodology has also been used to adapt existing intervention programs to increase the effectiveness. The process of adapting and implementing intervention programs is done with an identified group of peer-researchers. Davidson, Stayner, Lambert, Smith, and Sledge (1997) completed a research project that worked with consumers to explore recidivism. The program was originally created to decrease recidivism in a population of people discharged from an inpatient psychiatric unit. When no one attended the program the university researchers engaged a group of consumers who had several hospital experiences to explore their beliefs about recidivism. Based on the results they worked together to revamp and implement the program, making it relevant to the people it was meant to serve (Davidson, Stayner, Lambert, Smith, & Sledge, 1997). Crabtree, Wall, and Ohm (2016) published an article of a critical reflection of a PAR project looking at the effectiveness of an intervention designed to provide skills necessary for transition into the community after an extended time in a prison setting. The academic researcher worked with three residents of the prison to complete interviews, transcribe and analyze the data. The authors explored their different

views created by their different positions (example academic or prisoner) of the Intervention project, keeping notes as they conducted the interviews and completed the analysis. The paper explores the value and personal outcomes from the experience of working together to conduct research. The result of the process was that all four researchers gained valuable insight into the power of PAR research to explore different perspectives (Crabtree, Wall, & Ohm, 2016).

Cook, et. al. (2010) worked with the Texas Department of State Health Services to implement a program for people moving into community care based on the Self-Directed Care (SDC) model (Cook et al., 2008). The SDC model works on the principle that participants have control, choice, and responsibility for their care services and that that support services are free of conflict of interest. Rather than reimbursing providers for services provided, the participants are given the money directly so that they may purchase the services they want and need from providers of their choice. The money is dispersed through an intermediary and life coaching is a key aspect of the SDC program. A PAR approach was used with a group of primary stakeholders including a group from the University of Illinois at Chicago, the Texas Department of State Health Services, providers, consumers, advocates, and policy makers. This group completed a series of meetings to identify and solve problems and build consensus. Once the decision was made to create a pilot program, committees were formed from the multi-stakeholder group to work collaboratively on the development of the SDC program. Initial data indicate that consumers are successfully using the money to make mental health related purchases and indicate increase satisfaction with the program as compared to the

traditional service program. The authors identify the PAR process as an important aspect in the successful implementation of the program (Cook et al., 2008).

#### 4. **Social Action Group**

In 2008, Minkler et al. published an article about the Social Action Group (SAG) which was part of a large community based participatory research (CBPR) project related to moving people out of nursing homes in the state of Illinois. The SAG program was a peer-mentored self-advocacy program designed to help people with a variety of disabilities develop a conscious awareness of their rights as humans living with a disability and to help them feel empowered to request and coordinating the services they need to live within those rights (Charleton, 1998; Freire, 1993). The SAG program was shown be effective in teaching people with a variety of disabilities who were institutionalized that they had the power, and the opportunity to change their situation by joining together to fight the inequalities in policy and services.

In 2014, Lee, Hammel and Wilson completed a study looking at the impact of a program called Money Follows the Person (MFP) Stepping Stones on self-efficacy for 13 people with diverse disabilities. The MFP Stepping Stones program is a 10-week, manualized program that was created based on the transitional needs identified by Minkler et al. (2008) during the SAG project. Stepping Stones is designed specifically for people with disabilities who are living in a nursing home, in Chicago, IL, and are eligible for transition into community-based services as a result of the Olmstead decision. People with disabilities who live in nursing homes for an extended period are often denied privacy as well as choice, control and autonomy. Because of the nursing home environment, they are not afforded the opportunity to complete basic living skills such as

home management, nor can they participate in meaningful life roles (Lee, Hammel, & Wilson, 2016). The result of this denial is loss of self-confidence for community living and difficulty with self-direction (Reinhard, 2010; DePoy & Werrback, 1996). Stepping Stones was designed to help mitigate risk by empowering people with disabilities to develop strategies to address the barriers that threaten community tenancy (Lee, Hammel, & Wilson, 2016). The 10-week Stepping Stones program has been run by Access Living in Chicago IL since the state entered two consent decrees to move people out of institutions in the early 2000s. The program includes modules around disability rights and disability policy, access to housing and transportation, wellness and technology. Lee, Hammel and Wilson (2016) used interviewer-administered surveys and focus groups to assess the impact of participation in the Stepping Stones program on participants hoping to transition. Participants reported they felt satisfied with the program. In addition, there were several positive outcomes including higher self-efficacy in daily management, a greater sense of empowerment and more confidence when procuring community resources or managing daily living. Given these outcomes it would seem that the Stepping Stones manual provides an effective structure for introducing disability studies concepts to people in the psychiatric disability community. For this reason the program will be used to guide the introduction of these concepts to the participants in this study.

The goal of this study is to determine the impact of introducing disability studies to people living or working with psychiatric disability and to see if that knowledge helps shift the power and open the door to self-determination. Given this goal is action oriented, an emancipatory approach, particularly a participatory action approach is most suited to the projected outcome for two reasons. Participants will learn information that

has been shown to improve the sense of empowerment for people with disabilities (Oliver, 2013), and the process can put the group in a position to decide if and what actions they wish to take going forward. This prospect of being able to implement the study results immediately is referred to as Knowledge Translation.

#### 5. **Knowledge translation and intervention**

Knowledge Translation (KT) is defined several ways. The Canadian Institutes for Health Research defines it as:

the exchange, synthesis, and ethically-sound application of knowledge – within a complex set of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products and a strengthened health care system.

(National Center for the Dissemination of Disability Research, (NCCDR), 2005, p.1)

KT is a process and a strategy that addresses the gap between knowledge production and implementation of the results that often occurs with the usual process of research and dissemination in the professional journals. A significant aspect of KT is that beyond the traditional dissemination process it mandates coordination and process improvement within the complex system that is being studied and impacted by the research process. This requires facilitating systematic interaction between researchers and policy makers. Models of KT include a push model in which researchers produce products that tell stakeholders about the outcome. Other models incorporate the dissemination into the method such as program evaluation using a logic model

approaches or participatory approaches that engage service users as co-researchers or as research drivers. All KT models incorporate the process of dissemination as a key aspect of the research process (National Center for the Dissemination of Disability Research, 2005). Knowledge translation strategies are increasingly being used in the health and mental health research arenas and is a good overall construct for a study looking at fostering self-determination. A great example of KT is the use of collaborative inquiry which encourages participants to actively reflect on their reactions to the introduction of a topic such as disability and mad studies, and to identify action steps around what they learned. Collaborative inquiry will be the methodology used for this study.

#### 6. **Collaborative inquiry**

Collaborative inquiry (Bray et al., 2000) is a research method that is included under the participatory action umbrella. CI shares important characteristics with PAR, however, the approach differs in several ways. Collaborative inquiry, sometimes referred to as cooperative inquiry (Heron, 1996) aligns well with the emancipatory paradigm while also ensuring knowledge translation through shared knowledge production. In CI researchers, sometimes referred to as “co-subjects,” are a group of stakeholders who come together because they share an interest in the subject being explored. CI is characterized by rounds of inquiry made up of action and reflection groups. In action groups participants explore material of significance to their inquiry and in reflection group participants reflect on their learning process and the broader impact of learning the material in their work or life. Through repeated cycles the group strives to answer complex questions of importance (Bray et al. 2000).

The primary difference between CI and other action research projects is that CI is focused on the personal experience of the researcher rather than a traditional PAR project in which researcher collects data on others. In addition, unlike PAR where the goal is problem solving and effecting change, the primary goal of CI is understanding the topic being explored, and constructing meaning, through group reflection around the information learned and the experience of learning (Bray et al. 2000). Although it is possible to leave a CI group with a group action plan, the main goal of traditional CI is personal development.

The study proposed here intends to tackle the key concepts of disability studies, and self-determination using this participatory approach. The CI method allows the PI to introduce models of psychiatric disability that group members are not familiar with and reflection cycles can be formally analyzed to gauge the impact that learning has on members views and their personal development. The last section in this literature review is designed to synthesize the literature and link those key concepts to my dissertation study.

#### **G. Summary and Conclusion**

There have been attempts to educate providers and users on the benefits and evidence supporting user self-determination in recovery and most, if not all, agree it is beneficial. Programs designed to help users feel more empowered and self-determined show good outcomes evidence in terms of follow through and yet neither of these developments have had much of an impact on the power relationship in daily practice. Recovery and self-management programs, consciousness raising groups and programs like WRAP and PADS for service users are all considered valuable and beneficial yet the



medical model remains the prevalent model for care and more importantly for research related to mental health treatment (Borg, Karlsson, Tondora, & Davidson, 2009; Oliver, 2013). True collaborative helping relationships characterized by service users who are driving decisions in their care and collectively making decisions around how to decrease social barriers to self-determination and participation will foster self-determination. This requires providers who understand the inter-relationship of psychiatric impairment and social barriers and who are allied with service users in their quests to achieve not only freedom from institutions, but inclusion and belonging in their communities. Providers and medical researchers have set a dominate tone that requires service users to comply with treatment and overcome their challenges, often using basic human rights as a reward for overcoming.

Neither service users nor providers in the mental health system have had much exposure to the paradigm of disability as a socially constructed phenomenon. Services based on this paradigm would shift the focus of helping from “individuals who are limited by their impairments or conditions” to “individuals who require accommodations to perform functions required to carry out life activities” (DeJong & O’Day, 1999, p. 7).

...service recipients would be viewed as having a right to voluntary, recovery oriented services and supports, as well as personal assistants, job and education coaches and full access to information technology that would allow them to learn about and advocate for their rights while offering and receiving peer support. (Cook & Jonikas, 2002)

Research in mental health, much like service provision, has tended to focus on the mitigation of symptoms and finding a cure through medical or psychological means. This research project considers the value of introducing disability studies concepts to

both service users and providers using a collaborative Inquiry method. Analysis focuses on the reflective process of the group as they co-create a shared definition of disability. Up to now research around disability, mad studies or even self-determination and has not included collaborative input from both services users and providers. The combined group of participants provides the opportunity to assess if co-creating a new definition of psychiatric disability broadens the intervention focus thereby opening the door to self-determination for everyone in the helping relationship. What follows is the research method, the themes that came out of the CI process, and a discussion of those results.

## **II. METHODS**

### **A. Background and Setting**

This participatory research study took place at the Thresholds Community Mental Health Center in Kankakee, IL. Thresholds is a well-known community mental health center that was established in 1959 in the city of Chicago, IL. Thresholds provides support for housing, employment, general mental health and health care, and advocacy for people in recovery from psychiatric disabilities and substance abuse. In addition, Thresholds supports research related to intervention and community based support programs. This study took place at the Kankakee location, one of the 100+ locations in and around Chicago. The Kankakee facility has been helping people move out of two large nursing homes in the area that are considered Institutes of Mental Diseases (IMD), in compliance with the Williams Consent Decree in the state of Illinois. The Kankakee location provides a variety of services for members including Assertive Community Treatment, supported living and employment programs, the Center for Recovery which provides psychosocial rehabilitation (PSR), group homes, a temporary residential program to support transition from the institution to community tenancy and the New Freedom peer run drop-in center. They also have an affiliation with a local medical center to address the comorbid medical challenges of the population they serve.

### **B. Participants**

Participants in the study were purposely recruited from a convenience sample of people who work and participated in any of the programs offered at the Thresholds in Kankakee. The goal was to establish a prototypical group of people who were actively involved in the programs supporting transition from institutions to communities. The

participants initially included 12 people: 8 service users (SU); 2 professional service providers (SP); and 2 peer service providers (PP). Becker, Israel and Allen (2005) discuss the importance of attending to the relationship in research groups, in particular to maintaining equitable participation and open communication. The literature points to the inequitable power relationship between service users and service providers (Corrigan, et. al., 2012). For that reason, there was a conscious decision to double the number of service users to offset the power typically held by providers (Russo, 2012).

1. **Participant selection**

All of the participants (SU, PP, and SP) were recruited in the following manner. The investigator created a flyer explaining the research project and provided copies, along with a list of inclusion criteria to the Regional Program Director of the Kankakee community mental health program. The director distributed the flyers to a pool service providers and service users who fit the basic criteria. The flyer instructed people who were interested in participating in the project to call the principle researcher. The researcher conducted a phone interview to confirm that the person fit the criteria for inclusion. Once the required number of participants for each group were identified recruitment ceased.

Prior to the interview participants reviewed and completed the consent form and then filled out a demographic form that included their age, gender, race, education level, their role at Thresholds, and the number of years they were involved with the organization. Those who identified with a diagnosis were asked to share the label they identified with, how long they were in an institution and how many years they had lived in the community since if applicable.

Since 8 of the 12 participants recruited for the study were SUs who identified with a diagnosis of schizophrenia, bipolar, or schizoaffective disorder there was concern by IRB reviewers that some participants might not be competent to sign the informed consent. To be sure they understood the concepts in the consent form before they signed, they were asked to complete the Macarthur Competence Assessment Tool for Clinical Research (MacCAT-CR). The MacCAT-CR is a standardized tool for assessing the capacity to consent to participate in research (Appelbaum & Grisso, 2001). SU participants agreed to complete the assessment and none scored below the minimum scores required to indicate competence

## 2. **Description of service users**

The service users (SU) in the study were between the ages of 38 and 62. Five SU participants were men and 3 were women. All the SU participants had been members of Thresholds for over a year, several for more than 4 years. Of the eight service users, three identified as African American, one as Hispanic and Puerto Rican, and four were white. One SU participant had a grade school education, one had a high school diploma, four had some college, one had an associate's degree and one had a bachelor's degree. SU participants identified with different diagnosis including schizophrenia, schizoaffective disorder, bipolar, and post-traumatic stress disorder (PTSD). All SU participants experienced one or more years of living in an institution, the longest tenure being over 10 years, and all have lived in the community for at least one year since leaving the institution.

## 3. **Description of peer service providers**

There were two Peer Service Providers involved in the study. One PP

Participant had been at Thresholds in the capacity of peer provider for less than five years. The other PP participant had experience living in an institution before joining Thresholds as a member, first while living in the group home and then in the supported living program. After leaving the supported living program he trained for his current position as a peer provider. In total he has been involved with Thresholds Kankakee for over 10 years. Peer providers identified with the diagnosis' of depression, bipolar and PTSD. Both had college experience with one holding a master's degree. The PP participants completed Threshold Recovery training, Certified Recovery Support Specialist (CRSS) training and were Wellness Recovery Action Plan (WRAP) facilitators.

4. **Description of Professional Service Providers**

There were two professional service providers (SP) in the study. Both SP participants held master's degrees. One had worked with Thresholds in some capacity for nearly 10 years. The other had been there for less than 5 years. In addition to their degree requirements, SP participants completed Threshold's required Recovery Training. (Refer to Table I for additional demographic information).

**TABLE 1**  
**PARTICIPANT DEMOGRAPHIC INFORMATION**

Participant	Role at Thresholds	# years at Thresholds	Gender	Age	Education	Diagnosis	Yrs. in Institution	Yrs. in community post institution.
1	SU	1-5	M	62	Grade School	Schizophrenia	1-5 years	2 years
2	SU	1-5	F	57	Some College	Schizo-Affective Disorder	10+ years	3 years
3	SU	1-5	M	45	Some College	Schizophrenia	1-5 years	3 years
4	SU	1-5	M	41	Bachelor's Degree	Schizophrenia	Under 1 year	4+ years
5	SU	1-5	M	38	Associate's Degree	Schizophrenia	Under 1 year	3 years
6	SU	1-5	M	57	High School Diploma	Bipolar Disorder and PTSD	1-5 years	4+ years
7	SU	1-5	F	45	Some College	Bipolar Disorder	1-5 years	1 year
8	SU	5-10	F	44	Some College	Bipolar Disorder	1-5 years	4+ years
9	PP	1-5	F	51	Master's Degree	Depression and PTSD	NA	NA
10	PP	10+	M	43	Some College	Bipolar	1-5 years	4+ years
11	SP	5-10	M	43	Master's Degree	NA	NA	NA
12	SP	1-5	F	28	Master's Degree	NA	NA	NA

### C. Study Design

This research project employs an emancipatory methodology that fits well with the principles of Knowledge Translation (National Center for the Dissemination of Disability Research, 2005; Patton, 2002). Research that falls under the emancipatory paradigm is directed as much toward emancipation, or transformation through group

action, as it is toward the production of knowledge (Patton, 2002). According to Kitson (2008), there has been a longstanding imbalance between knowledge production and actual application of the results. Knowledge translation (KT) emphasizes “the exchange, synthesis, and ethically sound application of knowledge, within a complex set of interactions among researchers and users...” (NDCCR, 2005, p. 1). Through this approach KT addresses the gap between knowledge production and application, with a goal to produce more effective interventions (Masuda, Zupancic, Crighton, Muhajarine, & Phipps, 2014).

The study is a multi-step qualitative approach designed to capture the impact of introducing disability studies concepts to a combined group of psychiatric service users and providers in a community mental health setting. The first step consisted of individual interviews with each participant to gather baseline data around their knowledge of the study topics. The remaining 11 meetings took place over the next 6 months and incorporated a Collaborative Inquiry (CI) process facilitated with the combined group. Collaborative inquiry (CI) is described as a means for conducting research as well as facilitating adult learning (Bray, Lee, Smith, & Yorks, 2000). CI research consists of repeated episodes of action related to a research question, and then reflection on the experience of the participants during the action phase (See figure 1). CI is designed to encourage participants to provide ongoing feedback and input about the process. Rather than co-researchers, a term commonly used in participatory research, participants in CI are often referred to as co-subjects since the qualitative data that is collected and analyzed comes primarily from the group’s reflection of their lived experience of the preceding action cycle (Bray, Lee, Smith, & Yorks, 2000).



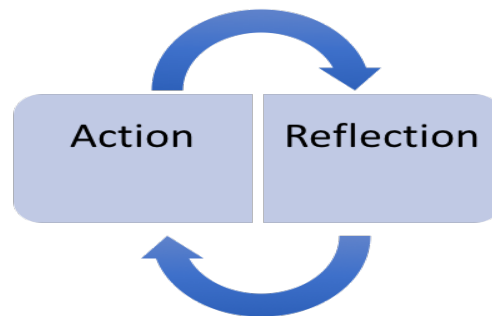


Figure 1: Action/Reflection Cycle

D. **Procedure**

1. **Interviews**

The interview was structured to capture the participant's baseline understanding of self-determination and the service system, as well as their understanding of human rights for people with psychosocial disability. Interviews ranged from 39 minutes to 110 minutes depending on the responses and response time of participants (see Appendix A for interview protocol). At the end of the interview, each participant was provided with a copy of the MFP Stepping Stones Facilitator's manual and a personal notebook to record private thoughts. They were asked to review the overall program before reflection group 1.

2. **Collaborative Inquiry**

After all the interviews were complete the study moved to the Collaborative Inquiry (CI) portion of the study. The initial group meeting was a two-hour

reflection group that started with discussing the power differential in a group given there were both service users and providers, and then establishing the guidelines for the CI process. The remaining group time was spent reflecting on participant's preliminary thoughts about the initial interview, and what they read in the Stepping Stone manual before coming to the group. Participants then attended two groups a month for the next five months. The first group each month was a two-hour action group with an education and discussion component around the study topics. A one-hour reflection group followed exactly one week later. The reflection group was scheduled a week after the action group so participants had time to think about and apply the information learned in the action groups if possible.

Action phases were provided in a teaching format. During the action groups, the principle researcher utilized the Stepping Stones manual along with additional handouts, film, videos and interactive activities to facilitate group discussions around the topics for that week. Additional materials were incorporated as needed to support the participant's understanding of the concepts in the Stepping Stones module(s) assigned for that month (see Appendix C for the lesson plans and handouts for each action group). The reflection groups that followed each action group were designed to encourage participants to engage in a process of shared critical reflection. The reflection group protocol began with a quick review of the action group topics to support the participant's recall of the information provided during the group. Remaining questions were designed to elicit feedback around how participants had processed and maybe applied the information. The groups could take the discussion in whatever direction they wanted as long as it was related in some way to the topics being explored. The principle researcher reintroduced

the questions from the original interview during the last reflection group. This gave the group members an opportunity to consider how their thinking had changed after having participated in the 5 action groups (See Appendix B for the guiding questions for the reflection groups). The reflection groups also served as a means for member checking to support the validity of the participant's interpretations (Bray et al., 2000). Table II provides a detailed summary and timetable for the CI phases. The PI's extensive experience in running groups with people who have psychiatric disabilities was important both when presenting complex information in the action groups, and in eliciting critical discussion and redirecting the flow of conversation from the inevitable tangents during the reflection groups.

### 3. **Data collection**

Initially all the groups were audio and video recorded. It was felt that this would allow the PI to capture the discussion as well as view the non-verbal cues of group members to assess for changes in the power relationship over time. By the end of the fourth meeting it was clear that intermittent video recording was sufficient for capturing additional information since there was a high degree of comfort amongst group members. All the groups were audio recorded. Participants were also asked to write down any additional thoughts they had in the personal journal provided.

**TABLE II****DETAILED TIMELINE AND CYCLES OF THE COLLABORATIVE INQUIRY  
PROCESS.**

<b>Timeframe</b>		<b>Process</b>
August – September 2016	Interviews	Complete individual interviews. Distributed Stepping Stones (SS) program copies to each participant
September 2016	Reflection Group 2 hours	Participants discussed the Stepping Stones program, the CI process, and reflected together on the topics and their thoughts after the initial interviews.
<b>CI Process</b>	<b>Phase 1</b>	<b>Process</b>
October 2016	Action Group 2 hours	Learning tasks around SS Module 1: Reframing Disability
October 2016	Reflection Group 1 hour	Reflected on what they learned during the first action group, and their understanding of the concepts in module 1 of the SS program.
	<b>Phase 2</b>	
November 2016	Action Group 2 hours	Learning tasks around SS Module 3: Disability Rights, History, Legislation and Resources
November 2016	Reflection Group 1 hour	Reflected on themes learned from the second work group. Discuss the impact of completing the first two action phases.
	<b>Phase 3</b>	
December 2016	Action Group 2 hours	Learning tasks around SS Module 4: Housing and Transportation Management, SS Module 5: Social Support & Networking and SS Module 7: Financial Management. Applied disability rights ideas from previous action groups.
December 2016	Reflection Group 1 hour	Reflected on themes from the first three CI cycles. The group requested more time to discuss models of disability and disability rights.
	<b>Phase 4</b>	
January 2017	Action Group 2 hours	Learning tasks touched on SS Modules 9: Health and Long Term Care Management and SS Module 10: Wellness and Health Promotion briefly then returned to disability and human rights concepts per request.
January 2017	Reflection Group 1 hour	Reflected on the action group topics from the previous week briefly and then focused on disability and disability rights and the meaning attached to words.
	<b>Phase 5</b>	
February 2017	Action Group 2 hours	Learning tasks touched on SS Modules 2, 6 and 8 – all on using Technology to Access Information. Learning tasks incorporated some of the earlier discussions of the participants that highlighted the challenges around disability and disability rights. Included a brief review of all topics.
February 2017	Reflection Group 1.5 hours	Reflected on the previous action group then revisited the questions from the original interview and reflected on them as a group.

#### 4. **Participant retention**

All 12 of the people recruited to participate in the study completed the interviews and 11 of the 12 attended the first two-hour reflection group. One member dropped out of the study after participating in the first reflection group because he obtained a job that conflicted with the times for the group. Nine of the 11 groups had at least 10 people in attendance. One group had only nine participants, because one PP and one SP had conflicts that came up unexpectedly, and one group only had eight participants as several people were sick that week. One member only came to five groups due to both mental and physical health problems. He stayed in contact with the PI however and expressed a desire to come and contribute when he was physically and mentally able to do so. This participant never missed more than two sessions in a row and as such there was no requirement to redo the consent process.

#### 5. **Research ethics**

The study was submitted and approved by the Institutional Review Board (IRB) at both the University of Illinois at Chicago where the principle researcher is a student, and Northwestern University where the principle researcher is a faculty member. Most of the data was managed by the PI. Audio recordings were transcribed verbatim and all the information that could potentially identify participants was removed. Audio and video recordings and transcriptions, as well as the NVivo software were stored on a computer that was purchased by the PI specifically for this study. The computer was encrypted and only the PI was able to view the data on the computer. One person was hired to help with transcribing the interviews. That person completed Collaborative Institute Training Initiative (CITI) training and signed a confidentiality statement. The

audio recordings of the interviews loaded onto an encrypted external drive by the PI and the transcribing was done from that drive. When not in use the drive was stored in a locked box in the PI's office. Only the PI and the person transcribing had access to the code for the lock box. The PI transcribed all focus groups on the encrypted computer. All other forms of data with identifiable information were kept in a locked storage box in the PIs office.

E. **Measurement**

Qualitative data for this research project was collected using audio recorded interviews, audio and video recorded reflection groups, reflective journals, and field notes.

1. **Interview protocol**

The initial interview was a semi-structured interview with 6 open ended questions that reflect the research questions. The overarching questions all had additional prompts to gather more specific information. Questions centered around the topics of recovery, self-determination, disability and disability rights, the experience of institution to community transition for people with psychiatric disability and the power relationships between service users and service providers. Topics were generated from the literature around institution to community transition and self-determination. At the conclusion of the interview participants were asked to make some suggestions for topics to include in an education program designed to improve the outcomes for people with psychiatric disability who were transferring out of institutions (Refer to Appendix A for the interview guide).

## 2. **Reflection group protocols**

Reflection group protocols were slightly different depending on the CI cycle. The first reflection group consisted of an orientation to the process of the study and generation of guidelines for the group. Remaining questions centered around the participant's impression of the Stepping Stones program, which they reviewed prior to the group. Lastly, they were asked to think about what they expected to learn over the next five months. The protocols for the next 4 reflection groups followed a general pattern. Each group began with a brief review of the previous action group learning tasks. Then there were several questions designed to help the group reflect on their thoughts after completing the learning tasks in the action group the week before. One of the questions asked the group to make suggestions for changes in the Stepping Stones module so people with psychiatric disability found it more relevant. That question was abandoned after the second reflection group as participants did not have any suggestions to offer. The final reflection group protocol included a revised set of questions drawn from the initial interview, designed to determine if there had been a shift in the understanding of the concepts of interest in the study. The very last question during this last reflection group did asked the participants to make some general suggestions for providing the Stepping Stone content to other stakeholders in the mental health service sector (Appendix B for the reflection group guidelines).

## F. **Analysis**

Qualitative analysis of the data in this study used an inductive thematic analysis approach (Patton, 2002). This approach allowed the PI to identify preliminary themes that

immersed early in the study and compare them to themes that emerged as the CI process progressed. The data that was analyzed for the study focused primarily on the 12 interviews and the six reflective groups, all of which were transcribed verbatim. The researcher considered transcribing the action groups however the group process included learning tasks, such as film, video and discussion in small groups, which was difficult to transcribe. Instead the principle researcher watched the video recordings and listened to the audio recordings both during and after coding the transcriptions, looking for words and statements either supported or refuted the themes emerging from the transcribed data, and to see if any additional themes emerged. The principle researcher also collected the personal journals of the participants; however, most participants did not use them. The three people that did, used them to take notes during the activities or to jot down their answers to the questions posed during large and small group discussions in the action groups. Neither the video recordings nor the reflective journals resulted in additional codes or themes.

#### 1. **Memos and Initial Codes**

In order to detect patterns in the data, the PI completed several rounds of coding, reading and re-reading the data, consulting others when appropriate, and then refining the codes and descriptions accordingly. The interviews and reflection groups, were transcribed verbatim and entered as internal data into the QSR NVivo data management program. The PI also printed a copy of the data and carefully read through it several times, noting general themes before beginning the coding process in NVivo (Charmaz, 2014). The initial review of the data began early so that the emerging ideas could be brought back to the group for discussion during the action groups each month



(Stringer, 2014). During the initial round of coding the PI went through every interview and focus group naming small segments of the data (Charmaz, 2014). This initial phase was helpful in establishing a list of words and ideas that could potentially be used as code names in the second round of coding. These thoughts and ideas were recorded as memos in NVivo and revisited several times.

## 2. **Attribute coding**

Round two of coding consisted of using NVivo to code the material for specific attributes that were important in the study. Attribute coding consists of basic descriptive data such as subject demographics, research setting, data format or timeframe (Miles & Huberman, 1994). NVivo allows the researcher to set up “cases” that can then be used to do comparisons in the analysis. Because this was a 6-month project intended to assess the impact of introducing new ideas that challenged hegemonic thinking, it was useful to compare the ideas and beliefs of different participants over time based on different attributes. Once the 12 people were programed into NVivo as “cases” each statement in the interviews and focus groups could be coded to a specific case. Cases were set up to include age, gender, race, years with the organization and the position in the program (service user, peer provider, or service provider). This allows analysis based on any or all of these attributes. In addition, every interview and focus group was coded for the month it was completed (Saldana, 2009).

## 3. **Descriptive and thematic coding**

The third round of coding involved a non-linear and reflective process of coding, re-coding, defining the codes, reflecting on definitions and quotes, redefining the codes, and then recoding some sections in order to assure that the themes that emerged

were a true indication of the data. The first step involved descriptive coding which was used to encapsulate seemingly important moments in the discussions. Descriptive coding (Miles & Huberman, 1994) is described as a short word or phrase that sums up a passage of qualitative data. The themes in the interview questions, along with the list of words generated from the initial phase of coding served as a starting point for generating names for codes, however, the PI did not specifically assign passages of data to those code names when doing the first round of coding. Instead, code names were generated based on the PI's first impression of the meaning of a passage. The result is that although many of the assigned code names did correspond with the list of words generated from the initial phase, the PI also generated new code names reflecting the themes that emerged during the focus groups over time (Saldana, 2009). At the end of this phase there were 57 identified codes.

To establish reliable results that truly reflect the research phenomenon under study the PI began the second phase of coding by narrowing down the themes. Codes that had a single data points were compared with other codes to identify similar phenomena (Saldana, 2009). Combining similar chunks of data and refining the code names reduced the number of identified codes to 36. In addition, the PI considered the relationships between the codes, arranging codes with similar themes together so there was a distinct overarching theme and several subthemes. These subthemes were aspects of the larger theme but were considered important enough to warrant calling them out for discussion. These segments of data were assigned more complex code names to reflect the patterns that were emerging (Miles & Huberman, 1994). At the end of this process the codes were reduced to seven major codes with anywhere from 2 - 6 sub codes falling underneath.

Using the data assigned to each code the researcher wrote detailed descriptions of the primary and sub codes. The quotes and descriptions were constantly compared to assure they remained a reflection of each other. This process further reduced the coding structure as the descriptions revealed that some sub-codes were essentially the same as others. The final coding structure consisted of 7 overarching codes with one to three sub-themes.

#### 4. **Trustworthiness**

Trustworthiness and rigor were address in several ways (Patton, 2002). Emerging ideas were presented to the research participants during ongoing action groups for further discussion. Memo writing during coding allowed the PI to compare the emerging themes with field notes taken during the CI process (Charmaz, 2014). The emerging themes were assigned descriptions based on the associated quotes. In keeping with the spirit of participatory research the emerging themes and subthemes were presented to 7 of the research participants for feedback and discussion resulting in further refinement of the descriptions of the themes (Cornwall & Jewkes, 1995). In addition, one person, who was not associated with this project but is a psychiatric nurse with several years' experience, was asked to read the descriptions of the themes and subthemes and sort them to determine how well they fit together. Based on her feedback regarding the fit between themes and subthemes, further revisions were made to the descriptions to ensure clarity. Another person, a student in the second-year occupational therapy class at Midwestern University in Downers Grove, who also had no association with the project, was asked to review a set of 40 quotes and match them to the themes based on the descriptions. When done she had sorted all but four of the quotes into the correct themes.

The four that were incorrect were sorted into a subtheme but fell under the correct, overarching theme. Based on the results the descriptions can be considered a reliable reflection of the data (Krueger & Casey, 2009).

## 5. **Conclusion**

The seven overarching themes and their sub-themes reflect a change in the participants understanding of psychiatric disability and indicate a small increase in their sense of self-determination over the course of the study. The themes that surfaced reflect the themes in the literature around Mad Studies that has emerged since this study began. In addition, the themes in the data suggest that some approaches to mental health support services and stigma reduction may actually be problematic. Using the NVivo software, an analysis was run comparing the three participant groups (SU, PP and SP) to each other. The results indicate that each group incorporated what they learned differently with service providers and peer providers showing the most dramatic difference in their thinking about psychiatric disability over the time of the study. Service users appear to struggle with letting go of some important hegemonic beliefs about psychiatric disability. The data provide some clues as to why this might be.

#### **IV. RESULTS**

The aim of this study was to explore how service users and service providers co-created a shared understanding of disability through a civil and human rights perspective, as a way to foster self-determination for people with psychosocial disability. The thematic analysis process resulted in seven overarching themes with 1 to 3 subthemes each. The overarching themes included: Belief that disability is in the person, barriers to community participation, power relationships, stigma around psychiatric disability, rethinking disability, humanity within disability and towards the future: "So What, Now What." These themes evolved over the course of the study with the last three themes emerging primarily during the second half. The later themes reflect the discourse that occurred after the group had been exposed to, and had time to discuss, disability rights and application of the social model to psychiatric disability. Figure 2 shows the relationship between themes and sub-themes. What follows is an analysis of the qualitative data for each theme including direct quotes from all types of participants, service users, peer providers and service providers to illustrate the theme.

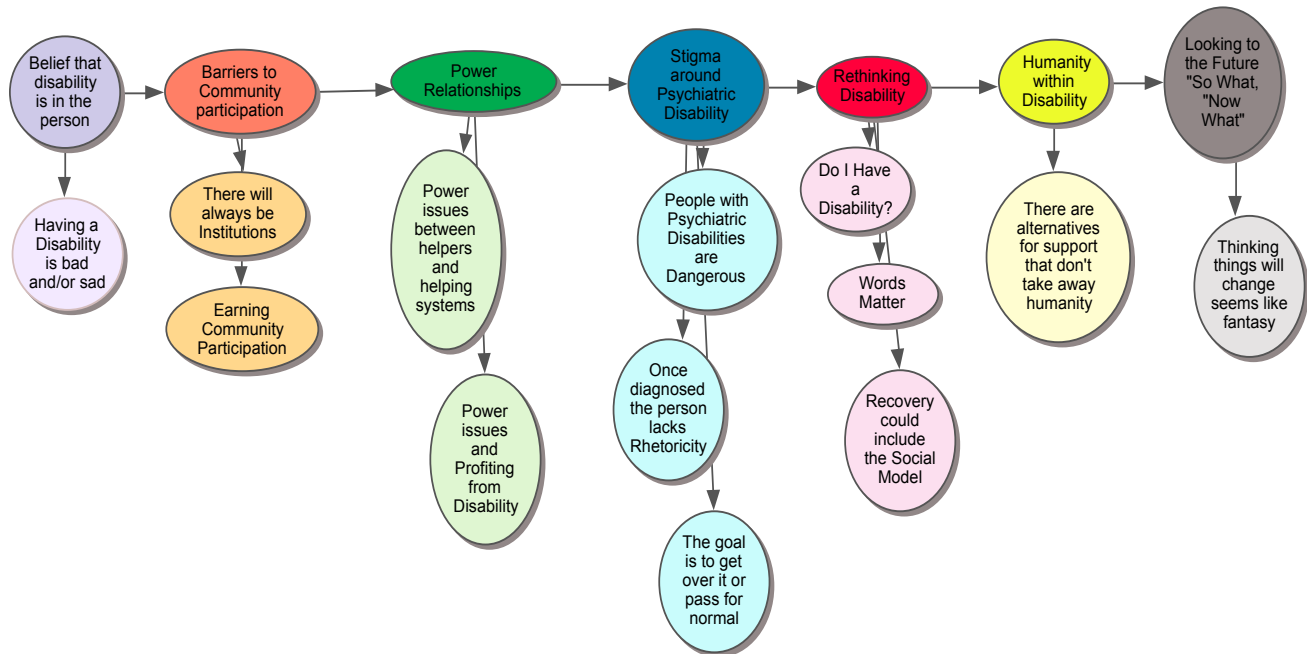


Figure 2: Themes and Subthemes

A. **Belief that Disability is in the Person**

The first overarching theme, belief that disability is in the person, reflects the prevailing belief about disability that emerged in the early part of the research. Statements around this topic indicated that participants viewed disability as both a personal responsibility and an undesirable trait. A number of the statements made in the interviews as well as the early reflection groups focused on diagnosis and the symptoms that hinder a person's ability to do the things they want or need to do.

A disability, I guess [is] –in general, not just mental health. Anything that just prevents you from being able to I guess function in the full capacity.

So, something that interferes with your life in a certain way (SP12).

Another participant said:

There are things I want to do, sometimes I need to do, in order to be whole, but I can't do it because of the disability I got. (SU1)

Participants believed that disability meant one must admit to needing help and resign themselves to be labeled in order to obtain benefits. Several statements indicated that disability meant people were unable to be whole, or independent, and required that they seek help and work toward getting better. One participant shared:

So the drawbacks (of disability) are it dehumanizes people, it makes you kind of a burden I think, right, if you can't fix it and people become a burden. (PP10)

The data suggest that participants associated the word disability with a physical impairment, which they considered undesirable. Participants described disability as a tragedy, a sad state or indicated that claiming disability was a bad idea that can lead to stagnation, a poor attitude or laziness. As a result of this association, service users expressed discomfort with any suggestion that they might identify as disabled people.

## **B. Barriers to Community Participation**

Barriers to community participation was another theme that emerged from the data gathered primarily during the first half of the project. All of the participants talked about attitudinal, social and systemic barriers to community participation that seem impermeable for people with psychiatric disability. Examples of barriers include the

impact of lengthy institutional tenancy, lack of services for those with a higher level of support needs, societal beliefs that stop people from full participation in all aspects of community living and the unintended consequences of medical, welfare and community policy.

I was attempting to join a church at one point and I was going through their membership classes. And we were going through the book and one of the chapters was if you have this problem, or this problem, or this problem, you will never be a full member of the church... because you do not, you cannot be competent enough to, to take a vote. (SU8)

Another participant shared:

I mean they got Catholic Charities, and DORS, and Addison Area. But still they can't live with them 24/7 and help them. You know, they only get a certain amount of hours. And if they use all their hours then they are out on their own. (SU8)

Another person identified disability policy as a major barrier. This participant is eligible for both Medicare and Medicaid but Medicaid only kicks in if she spends most of her monthly check on medical costs. That amount is referred to as a "spend down." She was told by the nursing home that her spend down would take her whole check leaving her with no money for rent or food:

When I was in the nursing home I applied twice for (local apartment complex that serves PWD) and got in, was able to get in both times. What it came down to though on leaving, was my spend down, that's why I could not leave. Because of my check and because of the spend down, it



was not feasible for me to leave at that time. And that's what kept me in for so long. (SU2)

Although service and peer providers were strong advocates for community-based care, the data suggest that prior to learning about disability rights people believed that long-term institutional care was necessary for many. Both users and providers believed there would always be people who are too "sick," or because of addiction were unlikely to be successful in the community. One service provider said:

I mean if they are not able to –if they do have like full supports and they are still struggling to even be able to take care of themselves then maybe then their needs to be some higher level of support there. (SP12)

The last subtheme, earning community participation, appeared to be influenced by the fact that all the service users had lived in an institution at one point and had moved out into the community with support from Thresholds. Their stories indicated that rather than seeing community transition as a human right, they felt they had earned the right to move out through hard work and compliance with required treatment, and they held others to the same standard. One person stated:

Okay well I think it has to be made clear that –that like I was saying before a certain level of responsibility and accountability, you know, comes,... with the degree of freedom,... and I guess, you know, having to pay rent and bills and buy food and hygiene products and so forth and you know, I mean I guess people have to understand that freedom isn't necessarily a given. You know? You know, they want the freedom and the autonomy but responsibility comes with it. (SU4)

Early on participants' statements inferred that there are people who don't want to be helped in the community, that people are complacent or that their poor attitudes will keep them in institutions. There was a general belief amongst service users in particular, that a person with a psychiatric disability must accept the consequences of their choices, and show proof that they can handle the required responsibilities for community living, sometimes to a higher standard than the rest of the population.

### C. **Power Relationships**

The statements included in this theme reflect the complex *power relationships* between the service users and both individual providers and organizations, as well as organizations that provide benefits and community services (like housing and utility support) and even community organizations such as churches. In general, statements indicated that service providers hold greater power, first because they are in a position to assign diagnostic labels that characterize people's experiences and actions as lifelong illnesses. But also, because providers and provider organizations have significant influence over the actions and attitudes of service users including beliefs they hold about themselves and about their situations. Providers are often in a position to reward symptom and disability management with greater privileges. The peer providers in the drop-in center are recognized as more accessible although the data suggest that peer providers who work on community teams tend to be less of a peer, taking on the power afforded to the service providers in the system. The following comments from service users illustrate the power theme:

...like in the psych ward you know, you can choose whether or not to take them (medications) but we're not going to let you go until you do. (SU4)."

“So you appease them [referring to the staff] and you take them there, but once you get out..., but the reality is are you going to [take them] or are you not? (SU2). “Because of the position you’re in you don’t really have much foundation or ground to have much of an argument or position against it... That’s the major issue you know, power, you know.” (SU4)

“...if someone is talking – say I am having a problem with sleeping, um, and a staff or somebody comes up “you know if you do this.” They don’t, they [staff] automatically just force you to do something, or tell you to do, um because they got more knowledge than you. And that’s what I struggle with....I like to be on the same level, I don’t want to be talked down to.

(SU8)

Another service user commented:

People deliberately go to you and try to provoke you, I mean, and do little things and then you know if you get angry or react you know, they can respond by saying “Oh, this person is symptomatic. (SU4)

It was interesting to note during the rigorous analysis of the qualitative data that the comments about power relationships between service users and service providers at Thresholds did not surface until midway through the CI groups. It seems that after working together during the groups, and discussing the disability studies concepts, the service users appeared to feel “safe” enough to share their views on power.

Statements by service users indicated that the experiences they have had in the mental health system, along with institutional and societal attitudes and actions, have contributed to the feeling that they are less than human. Participants pointed out how

their humanity was stripped from them when they were diagnosed and especially when they were institutionalized. The qualitative data analyzed here indicate that participants believe that regaining humanity, and the right to community living, work, and participation in the community, is possible only if they can prove they have overcome the symptoms of their illness and can conduct themselves well. One participant made this comment:

I feel the nursing homes just breed negativity because everything is the same and it's structured [by someone else] day in and day out to the same thing over and over and nothing changes. Your walls are beige and blue and that's it. Your bedding stays the same. The pictures stay the same. Nothing is changed, nothing gets, they [staff] might put a few holiday things up here and that's just it. Everything stays the same. (SU2)

Another participant points out how her feelings were dismissed:

Cause one of my original case workers, is long retired now. But she would mother me. There was no "we" talk. No, I'm right and your wrong and this is what you need to do. And it was a battle with her constantly because she was right, I was wrong. And more of, you know that I don't have children. And she would literally berated me for being upset on Mother's Day or on Christmas. And I am like 30 some odd years old and she is berating me because of the fact that "Well be grateful you don't have children, you don't have the responsibility" so how can you go from that to you know, yeah... and I went to the ups, I talked to her, then I

talked to someone higher and they would not switch me, because she was  
 “good for me.”(SU8)

This peer provider’s comment illustrated the sense that people with psychiatric disabilities are viewed as a societal problem rather than individuals.

One of the things that I think, and I’ve ah, I’ve touched on it with different people on various occasions is this, um, the philosophy of, okay let’s [staff] group people together and say okay everyone is a certain way you know, in this group And, and um even in institutions, like in nursing homes - Like putting people there and saying “hey you know you are not going to get better, you might as well face it, you can’t rise above this.” That’s one of the advantages I think I do have is I, I did spend time in a nursing home and, so I know a little bit about that sense of um, institutionalism, or loss of autonomy. (PP10)

The data revealed that all participants, but particularly the service user’s, are aware of how little power they have to make decisions and how the provider system, and society in general, benefits monetarily from their being disabled. The belief that those who profit from disability hold power and likely will never give up either profit or power, is a prevailing reason for why service users think things will never change. Examples brought forth by participants included cutting services that benefit those with disability to save money for municipalities, and how providers and particularly provider systems, profit from serving the disabled. This is illustrated by a powerful group discussion:

Who benefits from people being disabled?...well someone does (SU4).  
 It’s a minority group. (PP10)

Doctors. (SU6)

Doctors, pharmacies. (SU4)

The three percent, or the one percent. (PP10)

Insurance companies. (SU6)

Nursing homes....hospitals, pharmacies. (SU2)

Therapists, yeah, you know, so I mean I really doubt for the people who really have the power . . . (SU4)

And their major thing is to keep those beds full and to keep that rotating. If one goes out, two come in. That's how they do it. – boom, boom, boom.

It's a production line, one after another. Keep the beds full. (SU2).

One of the service providers commented:

But it's like it just seems like any time there is something out there for somebody with a disability it gets penalized, it gets taken away, it's the first thing taken away. (SP12)

Several participants describe actions by nursing homes that are done to deter people with psychiatric disability from being discharged to the community.

But my first job I mean you were, as a staff person, you were instructed you know, by management "you need these people here." You know, somebody is coming to you asking, you want to leave? You want to move out, I want to move out... I mean, you were supposed to a, you know, make people go through hoops, and like you said, "what are you going to do, what about this, what about that, are you sure, you know you can't do that."... But no, you can't let that person sign their AMA documents - I

am like “Oh -why do we have a document if we can’t let the person sign it? (SP11)

Well the people that are there, um, I think nursing homes are into people that come because it’s a business. It’s not a place that cares about people like it should care about people. It’s a business, like anything else, the more you put in the more get out of it. So, okay so, you, say if you keep somebody blind to the fact that they can come out, and then at least try to be productive, then they not going to never believe that they can come out and be productive when they never tried it. There’s people that been in nursing homes since they were kids. (SU1)

The theme power relationships is a complicated and complex theme that resulted from lengthy discussions during the groups, around the services that are available in the mental health system and society as a whole. The data indicated that participants returned to this theme several times especially during the first half of the project, but also toward the end, as they began to integrate what they had learned in the groups. The community-based mental health facility that supported this research project is working to shift power to members and member participants are happy with the services. However, the data from this study indicate that participants with psychiatric disability experience a power disadvantage no matter where they live or seek services. Of the seven overarching themes that evolved in the analysis this one included the most comments, by both service users and providers.

#### D. **Stigma around Psychiatric Disability**

The qualitative data on the theme stigma around psychiatric disability relay the degree to which stigma is entrenched in society, not just around psychiatric disability but disability in general, and explores the level to which stigma impacts daily life.

Participants statements indicated that stigma is something that becomes a part of a person's daily existence as soon as they are labeled with a psychiatric diagnosis. Several comments indicated that participants hold stigmatizing attitudes and beliefs toward their peers, and toward those with physical disability:

I was just going to say, it's like a dehumanizing quality when you say you're disabled period. You know it's just, it seems like with mental health issues there is an even greater stigma than all the other disabilities. You know, it's already dehumanizing but I mean for some reason it seems like mental health is like the most dehumanizing thing possible when it comes to all the stigmas that come with the term disability. (SU4)

Well for me it's like feeling like you're a second-class citizen. (SU8)

We're the bottom of the barrel. (SU2)

The data revealed that participants, both service users and providers, were disturbed by insinuations often made in the media that people with psychiatric disabilities are a danger to society. Participants statements indicated that this societal conviction impacted their social and vocational participation and their sense of belonging in their community. The following comments reflect the concern expressed by service users over this:



About, you know, the minute somebody blows somebody else up its' a mental health issue....Really?? 99 percent of the people with mental health issues do not go and blow people up.” (SU8)

“I mean seriously? The people who blow people up have an anger issue. It is not a mental health it is an anger issue. (SU2)

Well you know in, I mean I understand that we've got the people who have shot up the post office and taken people out in bars in stuff and the first thing they say is oh well you know, they have a mental illness. What, maybe one percent of the people who have mental illness are going to shoot somebody up. Really? Why would you really bring that up in the conversation unless there was something else going on. I mean, and even then it shouldn't be made public the way it is. Because the minute someone says oh well you know I have a mental illness the first thing they think of is oh, she's going to go get a gun and shoot us up. That just does not happen. (SU8)

Participants statements acknowledge that once diagnosed service users often lose the ability to be recognized as a credible person in the health system and in society. The term rhetoricity is use intentionally for this subtheme. To put it in context, rhetoricity is defined as the art of speaking effectively so as to come across as making sense, or as being likable and credible (Price, 2011). The data indicated that participants feel they lose their rhetoricity as soon as someone hears they have a psychiatric label. Participants' statements indicated that often their concerns and actions are interpreted through the lens

of their past or their diagnostic label, rather than being seen as a plausible response to daily life situations.

Well I know, but I mean in the medical world we're lower class, were second class citizens. I mean, you know, well we have a mental illness. Oh my goodness you're disabled, you can't make your own decisions. You can't do this... you know. Why don't, why is it always, always if you have a mental illness you can't do whatever you want. (SU8)

I mean, yeah, I mean like the label, no matter how much sense you are making or what good arguments you have for why you don't need to be here, your ability to convince somebody is kinda taken away from you (SP11)

Another participant stated:

They can hold you up to 72 hours. If the doctor still wants you there you go in front of the judge. And the judge isn't going to listen to me, they listen to the doctor. (SU6)

Despite acknowledging the perceived loss of credibility in the system the data indicated that participants continue to tell stories with the intent of proving they have overcome their psychiatric disability. Their statements implied an expectation that they achieve a level of normality to gain acceptance. This includes the expectation that they are seen as productive. Some of the participants insisted on telling these stories in the research group, a group made up of peers and providers they knew well. Two participants talked of wanting to appear normal:

Outside of here like at my job, I pretend that nothing's wrong and nobody knows. I try hard to really, I've only told a couple people you know, yeah, I have a mental illness, I'm bipolar or whatever. But, like, I don't want anybody to know so I try hard, I pretend to be happy and fine and do my job and stuff so nobody knows. "(SU7)

I think it is the way with society cause there's people on the outside that I talk to and it took me awhile but I told them you know I have this bipolar and PTSD. So (They reply) "no you don't, no you don't. (SU6)

This statement was characteristic of many of the comments by this service user:

I must fulfill my responsibilities. So I'll take a towel and I'll take a shower and get moving and get cracking...How I approach breakfast, it's not good for me and then, okay well I have to –I'm scheduled to work the front desk so I've got to be there. I've got to follow through with my responsibilities. (SU2)

Many of the service user's stories, about taking personal responsibility and/or overcoming their symptoms, came up during planned discussions around the civil and human rights of people with psychiatric disability, or while the group was engaged in an activity designed to explore the social determinants of disability. The data analysis showed that early on in the project these stories had an effect of shifting the discussion focus away from disability rights and the social model, back to personal responsibility for illness management. The data indicated that service users feel compelled to try and prove they are responsible and have overcome disability, most likely by both the mental health system and society. This may have been a significant barrier for the service users in the

study, as they attempted to integrate their new understanding of disability as socially constructed with their long-standing beliefs around recovery.

E. **Rethinking Disability**

The introduction to the Stepping Stones modules during CI cycles 1 and 2, on Rethinking disability and disability rights, appeared to have an effect on the group's discussions right around the half way point of the research project. About this time the analysis reveals a shift in the discourse and participants statements began to indicate a willingness to explore an alternative definition of disability. Participants became more interest in the social model and started to consider the value of identifying as a disabled people. Participant's statements revealed that they were becoming more aware of socially constructed barriers to participation in daily life, such as policies, and societal attitudes, and were shifting the focus away from their "illness" as the primary source of disability. This shift is clearly illustrated by this person's comment:

I know one thing that changed the way I thought about my disability was like many years ago, I made the comparison like when a person has cancer or has diabetes I would say well I don't walk around saying "I am cancer" or I am diabetes. So If I am saying I have a mental illness it's not so bad. But now I am realizing that its regardless of how I look at that, it's better to say I'm disabled? Is that what we are saying? (PP11)

Participant's comments began to touch on the value of identifying as disabled:

I have a disability, and then you can go on and move from there. And if they ask you questions I think that's how you change your little corner.

(SU8)

Yeah that's true too. It makes room for discussion versus... (PP10)

Providers view of disability shifted considerably as these comments indicate:

I think if you watch that video with the idea of social model disability in the back of your mind. Then you get a different message out of it. Not necessarily overcoming narrative but wow, look how F'd up society is that people are not giving people a chance. (SP11)

It puts the onus of fixing it on, not the individual, but society. (SP11)

Some of the provider's comments indicated they are beginning to incorporate the disability studies ideas into their practice:

I would say, like (PP9) was saying earlier. I definitely look for where the disability lies, not so much in the person, but outside the person. I would say that's probably part of the coming to these groups and talking about these things that has shifted for me. (SP11)

I was just discussing this stuff with my boss. About how I am seeing disability as barriers rather than um, as opposed to how I had been seeing it. And trying to relate that to mental health. So what would be, how could I remove barriers from my staff here at the New Freedom Center so they are not disabled by their impairments. So thinking of things like finding a quiet place they could go when it comes overwhelming. Or being okay with a flexible schedule of coming in later in the day for those of us who

are groggy in the morning from meds. And having a lots of twiddle toys available. (PP9)

The question “Do I have a disability?” was posed by a peer provider during the third (of five) reflection group when the group was sharing comments about how they were starting to think differently about disability. The data indicated that for the remaining half of the research project participants struggled to redefine disability as something other than a physical impairment. The group resisted the identity of “being disabled” in part because they still focused on symptoms which were episodic in nature, or controlled with medication. At the same time the data suggest that the group valued how the social model offered an explanation for their experiences of oppression. The prevalent belief that disability is bad and sad remained a major deterrent to changing their thinking about identifying as disabled. Participants suggested that when things were going well they could hide their symptoms and pass for normal. Identifying as a disabled person would essentially eliminate their option to do that.

One participant shared:

Okay, but even though your disabled but what if you can still do your job?

Do you still classify yourself as disabled? I feel like I can do a job and I

don’t really feel I fall under that disabled label any more. (SU2)

One peer provider grappled with this question for several groups. Her statements indicate her ambivalence:

I had the same question and wrote it down when I was doing the reading

[about Stepping Stones] actually, you know. Do I have a psychiatric

disability? I haven’t been hospitalized since the 90s. Um, I have, you

know, I've gone to school, I've gone to graduate school. I have a job.

(PP9)

Well you know, do I still have times when I go into depressions? Yeah!

That are disabling? Yeah! Which also brought me to the do I have a physical disability? Cause I also have a chronic physical illness, and that got me thinking. Is a chronic illness, does that mean disability, or is it an illness? I mean where is illness and where is disability? (PP9)

The other peer provider asked this question several times:

So are we saying as a group, it's better to say we're disabled versus saying we have a mental illness? (PP10)

The subtheme words matter reflects statements in the data that acknowledged the power that words have in constructing people's reality and ultimately their lives. Participants agreed that words like disability, mental illness and impairment influenced societal attitudes as well as their own attitudes. As peer provider stated:

For me it was um, seeing that, I mean in the past I use to say, well you know if you, whether you call a person, say a person has a mental illness or say they have a disability it's just words, it doesn't really make too much of a difference what label you put on people, even though I kind of sensed that it did make a difference, but now it's reinforced. It's really important to me that words that I attached to whatever a person might be dealing with, and seeing the person as human beings and individuals instead of just, okay this is, they're in a group and everything, yeah. So that words matter. (PP10)

Participants were initially opposed to the term impairment but after exploring alternatives, began to reconsider because they began to think the term addressed personal experience with disabling symptoms and personal responsibility for self-care, in a less stigmatizing and more inclusive way. The following comments illustrate that evolution:

I am really liking your term more, the emotional impairment. Not that it puts us any different than other people who have a disability but it makes more sense for most of us. It seems too. (PP10)

And that's what I was getting at because when I was talking about the different groups and how certain groups qualify and other groups don't where as if we had a more, I don't like to say impairment is more general, but it just covers, it's not as stigmatizing for one, which is important.

That's an important thing. But it's inclusive. More inclusive I guess.  
(PP10)

Although the participants expressed interest in the social and civil rights models of disability, the data suggested that they were not ready to give up the Recovery Model as treatment framework. At one point, shortly into the study, the participants recognized how, in practice, the Recovery Model has been strongly influenced by the medical model approach to disability. Despite that realization, participants maintained a desire to reconcile the Recovery Model with the disability concepts. This discussion was summed up by a service provider:

The idea of recovery could go hand and hand with the social model if you were doing something like where the social model could, as a society we could come together and help people in those recovery goals the living and



other things, it doesn't have to be recovery is more medical. It's just kind of the way it is running right now because that is the way it is functioning. But it could be easily transitioned too. (SP12)

Participants grappled with the implications of the social and civil rights approaches to disability throughout the second half of the study. The data showed that the service users in particular remained conflicted. They were not ready to give up their belief that acceptance comes with personal effort and overcoming and yet they recognized and appreciated the idea that marginalization it isn't their fault but the result of a society that discredits and fears people with psychiatric disabilities. The data from this project illustrate how muddled the term disability is for people whose lives are impacted by disability policy. In large part because medicine, social security entitlements and civil rights policy such as the American with Disabilities Act all provide conflicting definitions.

F. **Humanity within Disability**

The theme Humanity within disability is used as the overarching theme here because near the end of the project the participants began to view disability from a social lens. As a result, they began to voice their desire to re-establish their humanity in the face of a dehumanizing system. Statements suggested that participants had started to consider all forms of disability, even psychiatric disability, as a normal part of the human experience. One person summed it up with this comment:

Disability is a part of life, some will have them and some will not. And very few will not...If we all live long enough we will. That has really stuck with me...Because, we may all have disabilities now. But you know

what? It's going to catch up to the other ones who don't (group chuckles) who are laughing at us behind our backs right now. It is going to catch up to them folks. (SU2)

Another stated:

It's really sad. We're human. That's my thing is, we're human, whether we have issues or not we're human and people need to accept us for who we are. (SU8)

As the participants reconsidered the term disability, and contemplated their rights as human beings, the discussion turned to topics around service options that were considered less dehumanizing, particularly for acute crisis intervention, which they continued to view as inevitable. Participants agreed that if the service system treated people with respect for their human and civil rights seeking help would feel more accessible and less frightening. This discussion was introduced by peer providers with these comments:

It's, a crisis respite center, correct me if I am wrong (PP9) would be, the idea behind it is instead of when a person is in a crisis with a mental illness, instead of having to go to the ER they can go to the center where typically they'd have peers as well as maybe a clinical person or something, and they just go there and work through their crisis instead of having to go to ER and be hospitalized." (PP10)

...But the studies they have done at the original one which is in (area), they have had like an 86% hospital deflection rate. (PP9)

Service providers contemplated how a human rights approach would change supports for people with psychiatric disabilities:

...more varied. More community based. Support from you know, church communities, and neighbors, and um, families and whoever, the clerk at the grocery store, um, if everyone were supporting one another in terms of whatever issues people might have, how awesome would that be? (PP9)

I think, I was going to say people tend to be like - you need support. They don't think of themselves as "I am the support." Maybe if we were all thinking that way. (SP12)

Early data suggested that creating new services options, from a peer and community support perspective, hadn't occurred to many of the participants, especially service users. After the discourse in the group shifted from disability as bad and sad to disability as something that was a "normal" part of humanity, people in the group began to contemplate new service ideas. The data analysis suggested that the group found these ideas more plausible when they started from the perspective that disability was almost inevitable for everyone at some point in their lives, rather than as an abnormality that needed to be fixed or overcome.

#### G. **Looking to the Future: "So What, Now What?"**

The final reflection group began with a review of the topics in the Stepping Stones program and the discussions over the course of the project, however, the data show that participants were most interested in talking about plans for the future. The phrase "*So What, Now What*" used in the name of this theme came from a video that the

group watched in which one person changed a failing system despite the poor odds and limited resources. Statements in the data included short and long-term plans for what to do going forward, including what steps this group might take to influence attitudes and challenges in their surrounding community. This is illustrated by this conversation between group members:

And it's like the old way was "okay you're disabled. That's your label, that's who you are. You are a disabled person" Now it's like (SU6) "so what" (SU2) I have, I have a disability, so what. Let's not look at the label, let's look at what we can do to ah, to work with it and to be a member of society and, and stuff like that so. (PP10)

The following statements illustrate how members responded to a question by the PI during the focus group:

...if you understand disability as being outside of yourself, does that give you any more of comfort with like standing together as a group and speaking out – in this community?" (PI) "It motivates me (PP10)." and "is it time for us to stand up and speak out as a group? (SU2)

The data suggested group members felt their discussions about the social model during this project, especially the discussions around social activism, had a positive impact on their sense of empowerment.

When you, when I called to you, what was the, one of the things that I said to you when...I am here to help, I feel like I am the hope for the next generation. I feel like I've taken and taken and taken from the disabilities, and everything in my life and what I've balled it up to, it's time for me to

help. I went from take, take, take, to I'm going to save the world. You know that may be crazy but I'm going to save the world. (SU8)

However, participant's statements about feeling more empowered alternated with statements filled with doubt over whether things would really change, and if it was worth the effort to try. The data illustrated the participant's ambivalence and sense of overwhelm even while they considered the options they had for moving forward. These statements by participants, collected near the end of the project, illustrate this ambivalence:

We are talking about fantasy world now, it's not that way out there. It's been like that forever so, you know, what makes us think it was going to change?... (SU6)

I think it has...I mean let's face it we have gone from giving mentally ill people lobotomies, and ECT treatments still happen but they are not like they were...So you know, eventually we will get there. It is going to take time and it's going to take people who can talk about it and end it, end the stigma. And at some point, at somewhere we will. (SU8)

Overall, in the participants shared statements about the future, they expressed desire to change things and make things better for themselves and other people with psychiatric disabilities. Although they were often overwhelmed and unsure as to how to start, the group talked of hopes for the future and they felt as a group they had a voice and a platform for change.

## H. **Differences between Service Users and Service Providers**

NVivo software, the software program used to help code the data for this study, has a feature that allows for setting up and comparing cases across time. The participants in the study were set up as cases with attributes that included such things as age, psychiatric label, gender identification and their role at Thresholds (service users, peer providers, or professional providers). In addition to the codes assigned to them, each individual statement in the interviews and focus groups were coded for the person who made the statement and the month each statement was made. The interviews and the first reflection group were all complete in September of 2016. This allowed for a comparison of quotes from the baseline interviews and the first group in September, to the final group held in February of 2017.

### 1. **September 2016**

At the beginning of the study, nearly everyone agreed that disability resided in the person and was the primary barrier to inclusion in the community. All of the participants agreed that people had the right to move out of institutions with help, as long as they could show they were ready and willing. One of the service users stated:

You know, there's responsibility and there's accountability and so forth.

So, so I mean a certain level of competence and responsibility comes with autonomy, I think, so I mean I guess that there's experts that seem to kind of make that decision or whatever. (SU4).

Professional providers identified disability primarily as signs or symptoms that impair function as noted in this comment:

In terms of mental disability, I mean something, there may be some type of symptom of your illness that you experience that prevents you from doing, um, some type of activity of daily living or some type of, I mean I don't know, like work or something like that, of fulfilling some certain role that you, aww, whether that be a job, a student, a parent, some type of role function. Um, something gets in the way. (SP11)

## 2. **February 2017**

By the end of the data collection period the data analysis showed a notable difference between service providers and service users. The comments of both peer and professional providers indicated a significant change in their perspectives, away from an individual and medical approach to psychiatric disability, and toward an understanding of disability as socially constructed. Their comments centered around civil and human rights for participation and they spoke of restructuring their intervention strategies to include looking for social barriers and finding supports in the community, rather than focusing solely on personal responsibility. Peer and professional providers were interested in the implementation of a more inclusive model that looked at social barriers. One of the professional providers offered this comment:

Like how useful is the concept of recovery and focusing on, well, what kinds of supports are in place for a person to be able to live in a community? I think the last is more important and you know, if you get the right supports then the person will be able to reach their personal goals which is often times living in the community and I mean that's kind of the

important thing we are talking about – you know, getting out of the nursing home, getting your own place and how you do that. (SP11)

A peer provider made this comment:

Talking about recovery isn't necessarily the most important step in this process. It seems like it is more important to talk about, are, what kinds of things are going to happen, you know? What kinds of things do we need, um, which are supports and services in a lot of cases. (PP10)

Service user's comments toward the end also indicated that they valued what they learned about disability rights and several stated that they no longer felt ashamed of identifying with the term disability. One service user made this comment:

Well I mean recovery for each of us is different, um, but for me in the last few months I noticed that I am no longer ashamed of being a disabled person. It doesn't matter if it's psychiatric or physical or whatever. (SU2)

At the same time the data indicated that service users maintained their belief that community tenancy was a right afforded to those who took personal responsibility for their illness and were working to overcome their symptoms. One of the service users was very focused on personal responsibility. This comment was representative of many of his thoughts about psychiatric disability:

Well I mean, I think that before you can begin to help one, someone has to want to do better you know, I mean you can try to help them but if they don't want to do better themselves, if they don't recognize they have a problem or weakness, or issue then, I mean, you can try to reach out to them all you want to...I think what I am trying to say is a



person's attitude can be more of a disability than actually a mental illness can. (SU4)

Although service users were actively talking about doing things to change the social barriers to psychiatric disability they also struggled with identifying alternatives to the current system of care and were uncertain things could ever change for them.

Okay, I admit it's come a long way since the 80s. Before then they just locked your ass up, shut you up, doped you up, strap you down. Now the government has changed some of that but the government has not changed society. (SU6)

The data indicate that by the end of the study all the participants began to look for social barriers that form disability in the service system and in the community, and both were open to repurposing the words "disability" and "impairment" to reflect a social model approach. However, the data suggest that providers adopted the concepts more fully as they began speaking about how they incorporated them into their practices. Service users, on the other hand, had difficulty letting go of the medical model focus on personal responsibility and person journey. They also had trouble picturing the kinds of services that would allow someone to live in the community when they didn't show they were responsible (for their meds or their bills), or if they didn't demonstrate all the needed living skills to be considered independent,

## I. **Conclusion**

The seven overarching themes, and their sub-themes, reflect a change in the participants understanding of psychiatric disability over the course of the study. The data suggest that over time there is also a change in their sense of self-determination as the

group uses later meetings to discuss what to do going forward. The themes *power relationships* and *stigma around psychiatric disability* were the themes with the greatest number of coded comments. These topics came up during nearly every group which suggests that any revision of the Stepping Stones modules for psychiatric disability will need to address them. The results show that the concepts of personal responsibility for illness and overcoming were entrenched in the narratives of the service users in the study, and actually became a barrier as they attempted to integrate their understanding of the of the social model with their beliefs about psychiatric disability and recovery. The results also indicated that these narratives are perpetuated by the power structure in psychiatric service system. On the other hand, by the end of the project the comments by both peer and professional service providers suggested that they were starting to integrate the disability studies concepts more readily. The implications of these results will be explored in the discussion that follows.

## V. DISCUSSION

### A. **Introduction**

This study uses Collaborative Inquiry, an emancipatory research method to determine how a group of mental health service users and service providers co-create a shared understanding of disability through a civil and human rights perspective, as a way to foster self-determination. Based on the comprehensive review of the literature presented earlier, self-determination is a desired outcome of intervention regardless of whether the approach to intervention was guided by a medical model or a Recovery Model (Diamond, 2013). The literature does indicate that despite the development of intervention services meant to improve access to self-determination, the balance of power in the system hasn't shifted to service users (Chohen, 2016; Rose, 2016). Providers, and to a greater extent, provider systems, maintain the power to decide who gets what services and have much influence over how psychiatric disability and people with psychiatric disabilities are viewed in society (Chohen, 2017).

#### 1. **Research questions**

This study was initially guided by three questions. The answers to the first question will be discussed in detail throughout the remainder of this chapter. The initial second and third questions, related to the Stepping Stones program: *“Does the shared task of adapting the Stepping Stones program modules to reflect psychosocial disability result in a discourse that reflects greater awareness of the power relationship between users and providers in the study and in the community-based delivery model?”* And *“do the suggested changes to the Stepping Stones program reflect a shared understanding of disability from a civil and human rights perspective?”* were not answered in this study

given that participants did not provide any suggestions for changing the program. There may be a couple of reasons for this. Participants, when asked what they would change during the first two reflection groups, responded by saying they didn't have suggestions because the material discussed in the modules was new to them. By the third reflection group the Stepping Stones modules began to reflect barriers for those with physical disability, so although interesting, they didn't know of any equivalent applications for psychiatric disability. Participants indicated they were most interested in spending the time on the topics included in the first two modules: the social, civil, and human rights models and disability laws, rights, and resources. Over the course of the study much of the group time was dedicated to the group's efforts to learn and synthesize the disability topics and incorporate them into their current ideology around psychiatric disability and the mental health service structure.

At the end only the first research question *“how do service users and service providers co-create a shared understanding of disability through a civil and human rights perspective, as a way to foster self-determination for people with psychosocial disability?”* was fully addressed. It took longer than anticipated for participants to grasp these concepts, in part, because the participants have had little exposure to disability studies and disability rights, and extensive exposure to the medical model and medical terminology. Like the participants in a study by Beresford, Nettle, and Perring (2010) participants related well to the disabling impact of institutions and the marginalization, lack of effective services and poverty that are so problematic for them every day, but they had much difficulty with repurposing terms, like impairment and disabled to reflect a more nuance experience of psychiatric disability. During the final reflection group,

participants offered suggestions for how these concepts could be introduced to others in the psychiatric community. The suggestions were not specific to the Stepping Stones Modules but to the overall social and civil rights approach to disability and how it applies specifically to psychiatric disability. Those suggestions were incorporated into the themes generated during the research project.

## 2. **The collaborative inquiry process**

CI was chosen for this study because it is designed to facilitate participants reflections and open discourse. CI is a research method that began in education as a way to combine adult education and inquiry and it fits well with emancipatory research and research guided by the principles of knowledge translation (Bray, et al., 2000, Kitson, 2008). The emancipatory approach provided service users with a safe environment in which to share their views about mental health and gradually engage in discourse around more controversial topics such as power issues and their desires for self-determination. The analysis revealed that the opportunity for services users and providers, to come together to learn and reflect on new, and sometimes challenging topics, was particularly effective since the reflections combined views from both sides of the service relationship. The study was done over a period of 6 months which meant there were several weeks between the CI cycles. On the plus side the timing decreased the time burden on group members, especially the service providers who were staying after their regular work day to participate in this study. It also allowed for analysis between groups, permitting the PI to capture changes and address barriers to learning the material as needed. On the down side the group members often forgot details from the previous meetings. For this reason, each CI cycle began with a review of the previous month's topics before introducing new

disability studies concepts. The participants spoke of how much they enjoyed the meetings and discussions and stated they were pleased to have had the opportunity to learn the material.

Despite the natural power differences between service users and providers the group became very cohesive by the end of the second meeting. Having twice as many service users as providers appeared to have the intended effect of bolstering their confidence and they were very active and willing to take risks in the discussions. By the third reflection the service users were comfortable expressing their views, including being critical of their experience with providers over the course of their disability experience. It is difficult to speculate if the same level of cohesiveness and comfort would be achieved if the number of service users and providers were even. Also, starting with twice the number of service users meant that the cohesiveness and the quality of the discussions were not impacted when people missed a group here and there, or when the one person dropped out. To the surprise of the Principal Investigator, the two professional service providers were initially very quiet. The speculation is that providers are typically coached to allow service users to do the speaking in groups. After pointing out the importance of having everyone's voices in the study they became more actively engaged in the discussion.

## **B. Discussion and Synthesis of the Results**

There are several important connections that were identified after careful analysis of the qualitative data. Figure 3 shows some of the key relationships between the themes that emerged in the data. The discussion that follows covers three overarching views that encompass the connections and are worth discussing in detail as they are supported by,

and maybe can inform, the literature and debates around psychiatric disability and madness. The three views are titled: Adopting a disability and mad studies view; power, profit and hegemonic thinking: the challenge to self-determination; and the proposition of rethinking disability. This review uses the term Disability and Mad Studies throughout the discussion because researchers and theorist in this field are still debating if it is better to be included in the broader disability studies movement or whether there is greater advantage to developing a distinct discipline around Mad Studies (Beresford & Russo, 2016).

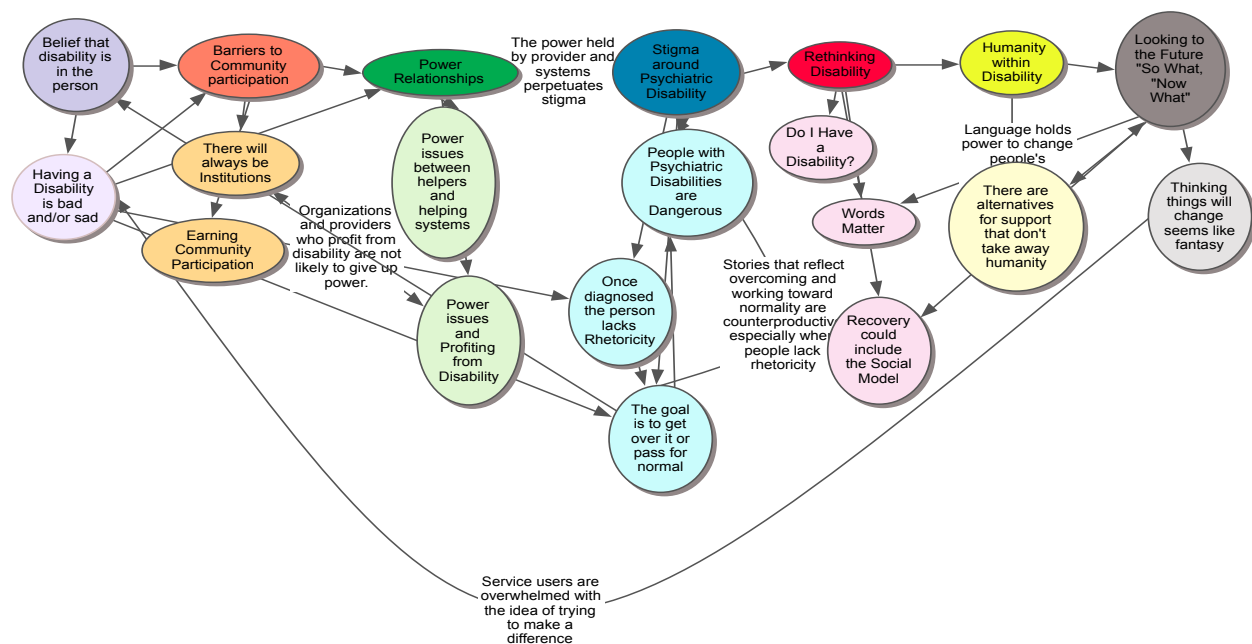


Figure 3: Themes subthemes and Connections

1. **Adopting a disability and mad studies view**

During this research study the first two CI cycles focused on the topics of Reframing Disability and Disability Rights and Resources. These two topics generated much conversation and many questions by participants, and provided a new lens for the reflections around recovery. However, when asked to shift the discussion away from the personal experiences of impairment to a more global exploration of the shared social and systematic experiences of those with psychiatric disability, service users, and for a while peer providers, were persistent in their view of recovery as an individual journey directed at overcoming the challenges of illness. In hind sight this discussion was valuable because the group explored commonly shared experiences within the mental health system with the advantage of having representation from both sides of the helping relationship. When the discourse intersected with disability studies concepts the PI was able to facilitate a more focused discussion around those concepts using the context of their shared experiences and diverse interpretations. By the third CI cycle the service providers, both peer and professional, began to view psychiatric disability with a broader lens. They spoke of ways they were incorporating what they learned about disability studies into their everyday experiences and stated they were becoming more aware of the disability experience overall. On the other hand, the service users remained focused on their personal experiences of beating the odds, overcoming symptoms, and earning the right to live in the community by proving themselves capable. This study, along with the literature on Disability and Mad Studies, offers some insight into why this is the case.

At the beginning of the process, nearly everyone was intrigued by the social model of disability and by the idea that as disabled people they were afforded rights by



law. It is important to recognize that the “social model” is an academic term and that the medical model has dominated the services received by participants. Nevertheless, participants quickly and clearly identified the barriers in their community, and in society, that impacted their ability to engage and belong to the community around them. They identified challenges with transportation, poverty, accessing healthy foods and mental health services and they agreed these barriers were disabling. Participants may not have known or used terms from the social model but they were very much aware of social and environmental barriers.

Participants were pleased with the community mental health services they received at Thresholds however they recognized that even Thresholds has limitations because of city, state and federal policies that, regardless of intent, marginalize people with psychiatric disability. For example, the apartments they were offered when they were transitioning out of the nursing home were limited. They leave the nursing homes with little money and typically have nothing to furnish an apartment. They must rely on state bridge grants and subsidized housing. The landlords in the Kankakee area know that Thresholds is dedicated to supporting people with a psychiatric diagnosis. Subsidized housing needs, combined with stigma of psychiatric disability often limits the housing options to less than desirable buildings and areas of town.

a. **Words matter**

For service users, one of the barriers to accepting disability studies concepts had to do with concerns about terminology which is embodied in the subtheme words matter. These concerns are documented in the Disability and Mad Studies literature (see Siebers, 2008, Beresford, Nettle & Perring, 2010, LeFrancois, Menzies &

Reaume, 2013). Proponents of the models of disability (social, civil rights and variation models) have suggested the use of the identity label “disabled person” to reflect that people are disabled by societal factors that don’t allow full inclusion for those who are fall outside what is considered normal (Linton, 1998). Beresford, Nettle & Perring, (2010) undertook a two-year study to determine what psychiatric service users thought about the social and civil rights approaches to psychiatric disability. Their results were very much in line with the results of this study. The suggestion that people with psychiatric disability are more disabled by social and policy issues, and are entitled to services regardless of ability, was met with skepticism. Participants’ statements indicated the ambivalence stems in part from the many definitions of the term disability. The consent decree that helped most of the service users in the study move out of the nursing homes is a direct result of the American with Disabilities Act. Yet most participants in this study didn’t know there was a connection between their moving out and the disability rights battles based on the civil rights definition of disability in the ADA. They had not considered disability as a political platform before this study. Disability as defined by the medical community is much more familiar. They understood disability as something that is not normal or natural and in need of fixing. For some participants, getting assigned a diagnosis validated their experiences and their belief that something was wrong with them. They felt a sense of relief because there was an explanation for their experiences, an illness, and with illness there is often hope for a cure.

The social security system on the other hand, defines disability as an illness, injury or developmental disability that interferes *with one’s ability to work at a job*. This definition appears to be most confounding for participants. Service users recognized that

their symptoms sometimes interfere with their ability to function, and they know they have to be considered “disabled” to receive social security benefits. At the same time, they consider their symptoms as transient, or in the case of many in the study, manageable through medication and other forms of treatment. They wondered if they are really disabled if they could work, although most of the service users in the study were not working. The question “Do I have a disability if I am able to work?” came up several times in the different discussions. The thought of identifying as socially *disabled people* didn’t seem truthful to them. Like the service users who participated in Beresford, Nettle & Perring (2010) study, participants in this study associated disability with people who had obvious physical impairment, and that was considered unacceptable. Although everyone agreed that the stigma people experience who have psychiatric disabilities was more detrimental to their lives than the stigma that people with physical disabilities experiences, their statements implied that they believed physically impairment was worse than “mental illness.”

b. **Impairment**

Although service users questioned whether they were disabled, they also clearly identified a need to *get over* an illness, admitting that whatever they had was not something good. The term impairment was introduced for discussion in the first action group on rethinking disability, as an alternative to medical illness. Like participants in the Beresford, Nettle, and Perring (2010) study, participants in this study grappled with the term impairment throughout all the groups in the study. Initially all participants interpreted impairment as a visible, physical difference. This may have been strengthened by the fact that all the films and videos used in the action stages of this

study were centered around physical and visible disability. Hours of searching and viewing film on psychiatric disability resulted in nothing that adequately addresses the socially constructed aspects of psychiatric disability or even invisible disability. Also, like the participants in the Beresford, Nettle, and Perring (2010) study, participants in this study didn't see a link between their view that people with psychiatric disability had something to *get over* and the concept of having an *impairment*. Participants started to reconsider the term impairment during the last action group. During this session, the group contributed to and compared two lists on a white board – one list was their understanding of the tasks associated with personal responsibility for illness. Examples of items identified for this list included taking medication, healthy eating, making and keeping doctor's visits, exercise and attending activities at the drop-in center for socialization. The other list contained societal and policy issues that they identified as disabling such as issues with public transportation, poverty, less than adequate options for living, and finding employment that was meaningful. Everyone agreed that items on the second list, which was longer, were responsible for a significant amount of the disability they experienced every day. Participants were somewhat surprised at how “normal” the items in the first list appeared. Very few items on the list were particular only to people with psychiatric disability. However, they did agree that people with psychiatric disability (and other disabilities) often have additional or more intense self-care requirements as a result of a difference or variation in their bodies and/or brains. They agreed that impairment might address their need for validation and their experience of psychiatric distress, although they preferred the term “emotional impairment.”

The social model is often critiqued because a purely social approach to disability effectively ignores the existence of pain and discomfort that can accompany impairment. Many people with disabilities, including participants in this study, wanted their experiences of discomfort to be acknowledged and validated (Shakespeare, 2017). Others in the study question the social model's lack of attention to impairment because they fear that not having a diagnosis would mean losing much needed benefits, something that other researchers in Mad Studies have found as well (see Beresford, Nettle, & Perring, 2010, Lefrancois, Menzies, & Reaume, 2013). Service providers in the group pointed out that the DSM criteria used to determine their diagnosis was created by a consensus of experts. This information, combined with the fact that many of the service and peer providers had, over time, received multiple diagnostic labels, opened the door for the group to consider how normal is defined. Mulvany (2000) speaks to this concept, pointing out that what is and is not "normal and natural" is decided by people who are considered knowledge experts – people with power. One of the concepts in the module that appeared to have a powerful impact on the participant's viewpoints around disability was the theory of human variation proposed by Tobin Siebers (2008). According to Siebers, the experience of disability is more likely than not, a normal human experience. The process of exploring the normality of disability, as something everyone experiences during their lifetime, was eye opening and proved to be a catalyst for reassessing their hesitancy around claiming a disability identity, instead of describing themselves as chronically ill. Although it would take more time, the participants began to reconsider their discomfort with the word impairment as well. Near the end of the study the group concluded that the word impairment was more neutral, more encompassing, and crossed

the disability experience which, if used instead of mental illness, might help decrease stigma.

c. **Recovery and the social model**

Beresford and Russo (2016) in the review of disability studies and madness point out that both the Recovery and Peer support movements were originally devised by psychiatric survivors to challenge professional authority and highlight self-agency. Participants in this study initially identified the Recovery Model as their model of choice stating that it reflected the concepts of the civil rights and disability models. During the first action group participants were asked to explore several of the interventions that are commonly used under Recovery, such as WRAP and PADS. Their thoughts coincided with what Beresford and Russo (2016) have suggested. They agreed that the recovery-based interventions were largely focused on personal responsibility for managing triggers and symptoms, much like the medical model. The recovery literature uses the term *personal responsibility* to describe the right to make decisions in response to life situations and challenges, and to experience and learn from the consequences of those choices (Kukla, Salyers, & Lysaker, 2013). However, the language used in the intervention literature often implies that personal responsibility is more aligned with compliance of self and illness management strategies. For example, the home page for the WRAP, a well-accepted peer intervention, explains personal responsibility with this statement: “It’s up to you, with the assistance of others, to take action and do what needs to be done to keep yourself well” (Mental Health Recovery, n.d.). Although the participants felt they had some choice and self-determination when it came to treatment and self-care goals there was always an underlying tone in their comments that people

with psychiatric disabilities need to comply with the expectations set by the provider community. More importantly, none of the evidence-based interventions considered during this action group addressed the societal and policy challenges that people with psychiatric disabilities find themselves living with (Beresford & Russo, 2016). The terms used in the Recovery Model, much like the term disability, have different definitions and connotations that can be confusing and even contrary at times (Davidson & Roe, 2007). In the end participants were unwilling to give up the tenets of the Recovery Model which they saw as life changing in psychiatric care. They believed that recovery could, and should, include concepts from the social, civil and human rights models of disability.

d. **Achieving the right of community tenancy**

One of the biggest challenges to reframing disability as a social, civil and human rights issue was letting go of the requirement that people must take personal responsibility for managing their illness and proving they are competent and responsible enough to handle community tenancy. Everyone in the group agreed that people were *human beings* and as such, had the right to live where they wanted. Yet even toward the end of the study, service users could not picture the system providing the necessary services that would allow people with very serious disability to realize that right. The requirement that people earn rights and privileges with compliance and good behavior has been a traditional part of inpatient and institutional psychiatric care for a long time. All of the service users in the study had lived in institutions and had move out with support from Thresholds, and their transition stories all included their efforts to prove they were ready. Also, nearly all of the service users in the study were doing well in the community and they regularly compared their progress to others who weren't

doing as well. One possible explanation for the resistance is that affording people the services they need effectively lowers expectations. People would be “allowed” to move out without having to meet the same standards as the participants in the study. Study participants nearly always told their moving out story with a focus on the pride they felt when they were able to meet the expectations. The “pull yourself up” attitude, however, is a powerful contributor to negative and disabling bias (Bay, 2017). Despite the discomfort of service users with the idea that people may be granted the right move to community living before they proved competent, they were please to realize they had the same rights. They took comfort in knowing that by law, they should not have to return to institutional living should they required a higher level of care.

## 2. **Power, profit and hegemonic thinking**

### a. **Power and stigma**

Central to the results diagram are the themes of power and stigma.

These two themes are most telling when it comes to addressing why stigma, access to care and humane treatment for people with psychiatric disabilities have not changed much despite new approaches to care. In fact, compared to the other emerging themes, service users had the most comments and discussion surrounding these themes. Like the literature on disability, participants in this study identified multiple power relationships, starting with the power that professionals have in redefining people’s actions and experiences as illness or abnormality (McGruder, 2002). McGruder (2002) gives the example of spending money, which is often identified as an illness symptom of mania without considering the role that spending money plays in our culture. Once someone is diagnosed responses to normal life experiences, sadness after the death of someone



important, or anxiety around medical challenges, and of course, spending money, are interpreted and often treated as symptoms of a diagnosed mental illness (Davidson, 2002). Diamond (2013) explores the language around psychiatric disability and points out how terms that describe everyday identities such as mother and worker are usurped with identity labels such as patient or ex-patient. Price (2011) traces the rhetoric that surrounds mass shootings and illustrates how the language used by police reports, court records and social media both draw on and perpetuate the societal bias that people diagnosed with mental illness lack insight, are dangerous and should receive treatment whether they want it or not. The participants in the study stated that most of the time they felt included by their case managers and teams at Thresholds. However, this was not the case in other settings. The participants identified many situations that illustrated the concerns written about by Price and others. Most of their comments were focused on their experiences in the different institutions in which they have been lived or been treated. In these settings, they described having little control over their environment, the people they spent time with or the decisions they made each day. Participants' comments indicated that in addition to losing choice and self-determination, there were times when they were punished with loss of privileges for not complying with the expectations. As a result of these practices, service users felt that providers did not see them as full human beings with human rights. Sometimes power was wielded through threats or comments about how they would fail in their attempts at community living, or by limiting their access to the information and supports they needed to move out of the nursing home in the first place. Participants described a number of other ways in which facilities and providers took away their sense of humanity including not providing for personal space, forcing

them to give up possessions that were important to them, not letting them personalize the spaces they were living in and not providing for their safety. Several participants stated they were sent to inpatient settings at times of crisis, to protect them from harm usually from themselves. However, not everything that was done in the interest of safety felt safe to them. Participants described inpatient settings as places where they were watched and documented on, where their behaviors and their experiences were interpreted negatively by others, where at times they felt they were being provoked to see what they would do, and where they or those around them were restrained if they became upset or angry, a practice that has been shown to perpetuate trauma (SAMHSA, 2015). They spoke of times when they had to accept unwanted help because providers, even at Thresholds, had different ideas about what was good for them. Service providers in the group also shared times when the organizations they worked for implement rules that were not in the best interest of the people they were serving. Examples included objectivity, highly structure facility rules (meal and bed times) without exceptions and withholding the information people needed and wanted to improve their situation and achieve a discharge from the facility.

b. **Profit and power**

One interesting discussion centered on the profit focus and resulting power in the provider system. Consistent with Longmore's (2003) observation, that many service organizations and businesses profit from disability, participants in this study observed that providers, provider systems and pharmaceutical companies were profit oriented organizations who relied on their illness and disability to make money, all while they lived in poverty. Participants also noted that city, state and federal

municipalities treated them less as fellow humans and more as burdens, cutting government and municipal funded services to save money, usually to lower the tax burden. One participant insisted several times that if changes in society require that someone has to give up profit then things will never change. Several disability and mad studies scholars discuss the challenge of power and profit (Chohen, 2016; Fabris, 2013; Longmore, 2003; Morrow, 2013) agrees with the participants in this study when she states that expecting psychiatry to give up power is an unrealistic expectation. The author's solution is to focus on breaking down the social structures that allow for the expansion of knowledge and power of expert psychiatry.

c. **The unintended impact of telling recovery stories**

Over the years stigma reduction around mental illness, has been the subject of numerous articles, books and activities. One of the most well accepted approaches is the approach that the National Alliance on Mental Illness (NAMI) has taken where service users tell their stories of recovery. These stories are intended to show the non-psychiatrically disabled population that people can overcome mental illness and live their lives. NAMI claims that these stories show there is hope for a "brighter future" with psychiatric disability (NAMI, n.d.), and encourage people to seek help. As with recovery, few of these stories address the social barriers to inclusion and nearly all include finding and complying with treatment as a precursor to living well. There is little support in the research to suggest that telling recovery stories is an effective means for instilling hope or decreasing stigma. Given the fact that stigma has not changed, or may even be worse in recent years, it can be argued that these efforts have not worked.

The tendency for service users to tell stories about successfully beating the odds and overcoming symptoms was common during the first four reflection groups in this study. In some cases, the stories told in the study group were about passing or hiding problems so as to appear as normal as possible. The participants were well acquainted with each other and had likely heard each other's stories during various group activities at the center. Despite that, some of the service users told, and at times retold their stories during the research groups, usually directing the conversation toward the PI. For two service users in particular these stories would surface each time there was a conversation around providing additional services for people who required more support needs to live and receive their mental health services in the community. The stories were often inserted into conversations while participants were working hard to learn and understand a new and challenging concept around disability rights or theory. The impact of that story would be to take the focus off social determinants or rights and place it back on the personal responsibility to improve. The tendency to tell these stories appeared to create a barrier to the goal of developing a shared understanding the social determinants of disability.

According to Veronka (2016) stories that subjugate mental illness or reflect overcoming of illness or disability only serve to complicate and even multiply negative beliefs about psychiatric disability. The author goes on to say that these stories draw on the power of psychiatric history without challenging it - and they do nothing to address social justice issues or change the root of "difference." Narratives that illustrate beating the odds and passing as nondisabled, are often sources of negative bias toward disability in our society because they perpetuate the notion that there is something "bad" to overcome or hide.

During the 4<sup>th</sup> action group, the PI brought some of the quotes from the transcripts and the group used the stories to explore theories of overcoming and inspiration narratives written by people with disabilities in the media. The group members in attendance that evening agreed that if psychiatric disability were to be considered a variation on human experience, rather than something that was bad and dangerous, there would be little reason to prove they had to beat it and “overcome the odds.” Some of the participants recognized how overcoming stories can actually thwart the intent of self-determination that is considered center to the Recovery Model approach. For example, the ability to successfully manage symptoms, emotions and daily responsibilities, prevalent themes in these stories, dismisses options such as a personal assistant (PA), an option that would open up community-based care and tenancy for people with high support needs

The resistance of service users to moving away from personal overcoming narratives and toward disability rights was not anticipated by the PI and that may have affected the time it took to reach a shared understanding of disability. Although everyone found they learned important information, only the service providers began to integrate the concepts into their daily activities. They began to consider successful community tenancy as combining self-care activities with community and activity support needs. Service users continued to hold onto the expectation of responsibility and self-management throughout the study period. Murugami (2009) states that the precursor to establishing a platform for and effecting change requires that marginalized populations recognize a shared experience of social barriers. This research supports claims by Murugami and others (see Price, 2011; Voronka, 2016), that narratives have a powerful

influence on how society views psychiatric disability. Storytelling appears to perpetuate power imbalance and stigma. This study suggests that changing the stories told by service users and providers could have an impact on empowerment and access to self-determination for people with psychiatric disability.

Overcoming and passing narratives, intended to show there is hope, or to convince society that people with psychiatric disabilities are credible and not dangerous, have been ineffective for another reason. This task requires undoing years of rhetoric by professionals and institutions that are considered valid and credible such as doctors, lawyers, pharmaceutical companies and public media. In 2017 the book, *Insane Consequences* by D.J. Jaffe (2017), was released to critical acclaim by physicians and treatment advocates in the medical system. Jaffe claims that taking money out of the psychiatric medical system and putting it into community-based services has effectively “forced” people with psychiatric disabilities into the streets (p.150). The book dismisses the research that supports community services and self-determination and makes a case for returning to coercive treatment practices for the sake of both those with mental illness and society. Jaffe’s rhetoric, by virtue of his credibility, will hold significant power over any collection of stories that show people can overcome and live in the community. Beresford (2004) points out that once people are labeled with a psychiatric diagnosis they struggle to be taken seriously anywhere. According to Price (2011) when people are diagnosed with mental disability (both psychiatric and intellectual) they lose their rhetoricity – their right to be considered valid and credible. This was born out in the discussions during the reflections. At the same time that participants telling their stories about how they beat the odds, they were also pointing out how little credibility they have

in the system. Participants told stories of doctors not listening to their medical concerns once they learned about their mental health diagnosis or interpreting everything with the lens of “mental illness” even if their response to a life situation would be considered as normal for those without a psychiatric label. They stated that in treatment settings they were often left out of decisions made on their behalf and they even lost credibility with family, friends and coworkers once people learned of their history. Jones and Robin (2014) point out that the simplified portrayal of “an illness that can be overcome” in these stories only serves to exacerbate stigma because the stories tend to increase the perception of seriousness, permanence and dangerousness. One of the peer providers validated these ideas when he stated that rather than hope, he feared his story might make recovery sound unachievable, especially when people lacked the resources he had. Jones and Robin point out that as stories in disability studies have moved toward portrayals of theory, art, and culture, the stories around psychiatric disability remain focused on treatment, rehabilitation and recovery (Jones & Robin, 2014). This research study provides evidence to support the notion that changing the narrative from overcoming or hiding illness to one that highlights psychiatric disability theory art, culture, and identity, much like the disability movement, could do two things. First these stories might lessen the perception by the public that psychiatric disability is bad, and scary. And second, the stories of art, culture, theory, and identity would support a shared identity and open the door to a more collaborative approach to social justice issues and ultimately to achieving community tenancy and self-determination.

### 3. **The proposition of rethinking disability**

The themes rethinking disability, Humanity within Disability and Looking to the Future “So What, Now What” all emerged during the last two reflection groups. Toward the end of the study the peer and professional providers were using very different language. All participants began to speak about looking less at the deficits in the person and focusing more on inclusiveness and barriers in society. Discussion included ways to recognize social barriers in WRAP plans and other Recovery-based programs and to recognize where power sits in their relationships with service users. Service users expressed feeling more empowered after learning about disability rights although they held onto their belief that community tenancy is earned through hard work and overcoming the illness. Everyone in the group acknowledged the power of the provider systems and society to construct the reality, identity and living situation for service users and they began to talk about what they could do. The discussion started to move from fixing impairment to exploring service alternatives that truly allowed for self-determination, like respite centers that help people avoid the stress of emergency rooms and hospitalization, and PA’s for people with greater community support needs. During the previous (final) action group, the participants had watched a TED talk called “So What, Now What” (Cliatt-Wayman, 2015). This became part of the theme because the participants repeated this sentiment several times during the final reflection group, while discussing ideas for the groups next steps. Several members of the group expressed interest in continuing their alliance. They started brainstorming ideas for future activities, including contacting their state representatives to educate them on psychiatric disability rights, having a barbeque and inviting some of Kankakee’s first responders for a meal



and comradery, participating in a discussion about psychiatric disability at a local university and holding a rally in the Kankakee community. Throughout these discussions people occasionally expressed feeling overwhelmed, pointing out that the task of changing society seemed impossible. Others countered with examples of how things had changed, for example, they had all been moved out of institutions. They also noted that the as a group, they had changed. They had gone from talking about the past to looking toward the future, they felt more connected and were making plans to do things in the community. Two people noted they had started to think more about working together to do good for everyone and spent less time focused on their problems. Overall group members stated they felt more connected through a shared platform that motivated them to try and do something, even if the changes were small.

#### 4. **Differences between service users and service providers**

This project started out with an assumption that it was important to introduce disability studies concepts to both service users and providers, together, because both actors have a role in perpetuating the current power relationship. The study results suggest that introducing the concepts to a mixed group is likely to be effective if the goal is increased self-determination. All three groups agreed that the social model, and knowing about disability rights, made a difference in how they viewed themselves and each other, and their respective roles in Thresholds and in the greater community. One important difference between the providers and the service users emerge over time. Service providers, both professional and peer providers began to look increasingly at the fit between the person's disability and the environment, and to take note of the barriers to, and needed support for successful community tenancy. At the same time, several

service users held onto their belief that people in institutions could not move out if they couldn't prove they were competent enough to manage their symptoms and their responsibilities. This insistence may be a product of two things; a system that demands compliance and a society that devalues disability and difference and values normativity and overcoming (Mulvany, 2000). Service providers have had a strong influence in what service users believe about themselves and about psychiatric disability. It seems to follow that if providers attitudes and ideas change first, and they began to approach services from the perspective of finding the fit between disability and environment, then service users are likely to change their narratives as well. However, powerful messages about personal responsibility and earning rights and privileges, perpetuated by providers in the mental health system are not so easy to undo. The current system appears to create a sense of competitiveness by awarding privileges (and sometimes better services) for compliance and good behavior. Opportunities are offered to people who meet a set of standards that not everyone can meet. In this atmosphere making the case that you are better may be an important survival strategy. Also, the service users in the study may be interpreting the additional supports and accommodations as an unfair advantage. This idea requires further discussion and research.

##### 5. **Self-determination theory**

This study was designed in part to explore ways in which introducing the disability studies concepts to the participants would have influence self-determination for service users. Given the nature and the short length of the research project it is difficult to say if there was any immediate influence in how participants perceive self-determination in the system. No verbal expressions or narratives specific to self-determination were

observed and no measures of self-determination were included. The 6-month project did not include a long term follow up, and as the themes indicate, it was only during the last two months that participants began to integrate the disability concepts into their understanding of psychiatric disabilities. However, a number of indicators suggest that introducing disability studies concepts to service users and providers could potentially benefit participants self-determination both as they seek services and as they make their way in the community.

During the latter two reflective groups service users began to discuss things they could do to make a difference. The conversations produced several ideas for action geared toward improving community inclusion. Examples included putting on a rally, inviting congressional members to Thresholds for a town hall meeting, and having a BBQ with first responders to develop a relationship that could potentially improve interactions during emergency situations.

Another indication that introducing disability studies concepts could increase access to self-determination for service users was the fact that professional and peer service providers began to alter their narrative about psychiatric disabilities to include the social barriers and supports for community participation. Throughout the study service users were very comfortable speaking up in group, and over time spoke openly about their negative experiences at the hands of service providers over the years. Yet much of their recovery narrative was built around compliance with treatment and follow through with recommendations. This narrative is a hallmark of the way mental health services have been provided for years. People are assessed to determine the problems, treatment goals are established to fix the problems and the service users are monitored to determine

if they meet the goals and develop the competence for discharge to the community.

Services users are conditioned to believe that they must prove competence in order to be granted opportunities. It stands to reason that if providers shaped the current narrative, they are also in a position to change it going forward. If providers, like the ones in this study, begin to address the social and community barriers to participation as the primary sources of disability, then it might be assumed that service users will also adopt a more disability aware view, and will feel comfortable taking more initiative to direct their own lives.

Lastly, when comparing the themes and subthemes found in this study with the components of self-determination theory an argument can be made that as people become more aware of the social, civil rights and human variation models of disability they are likely to become more internally motivated to self-advocate and to advocate for others.

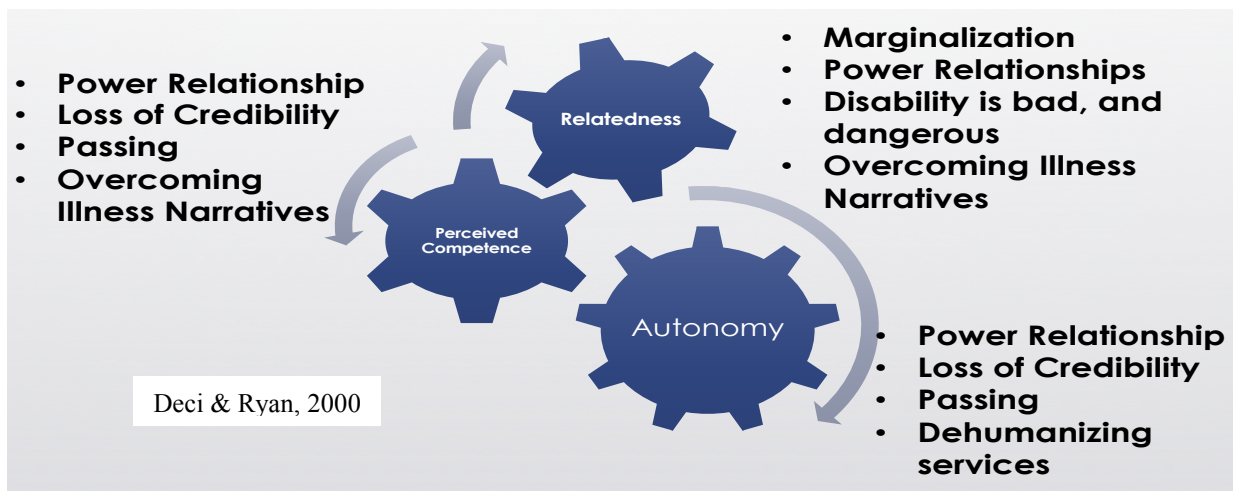


Figure 4: Self Determination Theory and the Themes and Subthemes of this Study

Figure 4 aligns the themes and subthemes with the components of internal motivation that are likely to be impacted. For example, power relationship and narratives that focus on overcoming symptoms are paired with perceived competence because study participants indicated that providers have the power to define competent behavior and to negate the explanations of the behavior provided by the service users. In addition, often providers and policy makers encourage the belief that symptoms are bad and dangerous and must be overcome for service users to achieve full participation. Under this system people who are not successful can be labeled incompetent and then subjected to institutionalization. Institutionalization and marginalization negatively impact the SDT component of relatedness because they keep people from valued positions in society. Relatedness is also impacted by the fear engendered by the medical community, policy makers and factors in society that perpetuate the belief that people with psychiatric disorders are dangerous. Lastly, despite attempts to shift power through interventions such as WRAP and PADS, it was clear by the results of this study that autonomy is still inaccessible for many because of the beliefs of and the power held by some providers, policy makers and organizations in society negatively influence the narrative, often characterizing psychiatric disability as bad and dangerous thereby justifying the coercion that remains in the system.

### C. **Conclusion**

The answer to the main research question, “how do service users and service providers co-create a shared understanding of disability through a civil and human rights perspective, as a way to foster self-determination” has a complex answer. Participants agreed that the discourse around mental illness and disability would benefit from a

broader definition and understanding of disability as socially constructed. Professional and peer providers were able to assimilate the information more readily into their belief system which may be a good thing given the power providers hold in constructing public narratives around psychiatric disability. If providers shift their focus and begin to recognize and address the social supports and barriers to living with psychiatric disability, service users will be more likely to reframe their personal identities as disabled people. That could open the door to greater self-determination in the services and community. The results of the study also suggest there is value in presenting this information to a mixed group of providers and service users. Participants found the small group activities and discussions more valuable when done together. They agreed that insights from both sides of the helping relationship challenged long held beliefs they had about each other.

One of the more important outcomes appears on the surface to have little to do with the original questions. The results of this study suggest that proponents of stigma reduction need to reconsider their reliance on the use of overcoming stories. This study, combined with previous literature would suggest that overcoming narratives serve only to increase the public's perception of the seriousness or dangerousness of psychiatric disability (Voronka, 2016). Overcoming stories also put up a barrier to developing a shared disability identity which according to the literature on Disability and Mad Studies, is a precursor to forming a more powerful platform for change (Mulvany, 2000; Longmore, 2003). Stories are a useful means for creating public perception. This research, along with the literature would suggest that stories focused on psychiatric disability theory, art and culture would be more effective in changing public perceptions

of people with psychiatric disability, connecting people with others who have disability and providing a shared platform and opening the door to greater self-determination.

**D. Reflections on the Role of the Investigator**

Collaborative Inquiry emerges out of the emancipatory paradigm which begins with a built-in bias that there are concerns around power within the system surrounding the participants (Patton, 2000). Collaborative inquiry, because of the focus on adult education, also assumes that participants are not familiar with a certain topic and that introducing that topic will impact the beliefs and actions of those participating. In a traditional CI process, the area of interest, and the learning tasks are generated through discussions among the participants themselves (Bray, et.al., 2000). In this particular CI study, the investigator selected the model and topics and guided the discussions utilizing the Stepping Stones curriculum. It is conceivable that the presence, and the decision making of the investigator represented a power figure in the process thereby playing a critical role in the outcome of the study.

In this situation it is logical to assume that study participants were not only unaware of disability studies concepts, they were not necessarily concerned with changing how they thought. Given this understanding, the PI planned out the learning process, established the learning tasks for the action groups and provided structure in the reflection groups in order to stay focused on the topics being taught. Essentially the PI, as the group leader of the action groups, was completely in control of the information being provided to participants around disability studies. Although this was the intended plan, to bring disability studies concepts to service users and providers to understand how it influenced their thinking, it is important to note the potential power position held by the

PI who is an academic researcher , a professional mental health provider and an experienced group leader. The leader position inherently holds the power to determine the content of the group discussions, and manage the dynamics to achieve the desired outcome. There is potential for the PI to go beyond educating and understanding the results, to imposing her bias on participants.

To address this challenge the PI kept reflective notes from each encounter and listened carefully to the audio recordings after each session, and again before the next one. Listening to the audio was an important aspect of this process since voice tone can be as important as words in influencing others. These thoughts included reflection about instances when the PI's interaction with participants might be interpreted as going beyond educating them on the constructs to influencing their beliefs. This reflective process allowed the PI to develop an awareness of, and to plan ways to mitigate moments where there was greater potential for overstepping her roll. Despite the investigator grounding her study on principles of CI (Bray et.al., 2000) and CBPR (Cornwall & Jewkes, 1995), her presence influenced the process and the themes that emerged.

#### E. **Limitations of the Research**

One of limitations of this study has to do with participant representation. The service user participants were chosen based on criteria that required they be able to participate in one or two-hour discussion groups, and do so along with 11 other people, some of which were providers. The desire to attend that long, the capacity to comprehend the complicated concepts taught or even the willingness to speak up within a diverse group of people, are not characteristics shared by everyone with psychiatric disability.



The participants who were chosen have done well in the community mental health program and all but one were thriving in the community. As such the views and beliefs of this group do not necessarily represent the views and beliefs of everyone in the population.

Another limitation was related to the Stepping Stones program. Despite attempts to include people with all different disabilities, the program is very much geared toward physical disability. All of the examples and media resources used in the program focused on people with physical and sensory disabilities and this created some confusion for a few of the members, especially those who held stigmatizing attitudes toward physical disability. In addition, the three modules covered during the third month of the study were focused on self-care, housing and transportation. These topics are commonly covered in the everyday activities of the members in the group and were of little interest to them in this particular process. The PI was focused on following the original study design and as a result was slow pick up on their disinterest. This was a missed opportunity. Focusing more time on the social, civil and human rights models, concepts that were more challenging for them to understand would have been more helpful and were of greater interest to members. Providing a slower paced introduction to the models of disabilities, with resources geared more toward invisible disability, would have strengthen the education portion of the study, helped the participants understand the concepts more thoroughly and allowed for deeper discussion.

Lastly, the CI cycles of action and reflection groups were spread out to decrease the time and cognitive burden on group members. Although this was helpful for the service providers who had productivity requirements, everyone tended to forget the

details from the previous group. This meant the PI had to spend time reviewing pertinent topics from the week before, adding in another opportunity for imposing her bias on the group and taking time from discussion. After experiencing this challenge during the first collaborative inquiry cycle, the PI was careful to intentionally plan the review, covering all of the important discussion points from the previous group in the shortest time possible. Holding the groups closer together and decreasing the amount of information covered in each group would be a better approach in future projects like this.

#### F. **Implications of this Research Study**

This study set out to look at how implementing a disability studies curriculum can facilitate self-determination. Participants comments indicate that the discussion they had together did lead to a greater sense of empowerment. They felt that after learning about disability studies concepts they felt more compelled to join together and fight for changes in the community. There are several implications to consider as a result of this project.

The first recommendation is to develop a program modeled after the Stepping Stones but with modules that better reflect the unique experiences of people with psychiatric disability. The results of this study suggest that the program would be most effective if the focus was primarily on disability rights and resources. The information in the skill building chapters are often covered in other programming experienced by this population. Like this study, a collaborative inquiry approach would work best and should include both service users and providers, together, to facilitate a shared understanding of these concepts, and to explore the power relationships. The participants in this research study stated that the modules on reframing disability, disability rights and resources and the information on disability laws and policies were very important. Modules on sources

of power and control in the system, e.g. the power of expert knowledge, the power of profit, and the power of words to create a person's reality would be an important addition. Lastly, the program must include a module exploring psychiatric disability culture, art and theory, and must include how to tell stories that connect people without perpetuating stigma and the power of the psychiatric system.

Another recommendation is to make Disability and Mad Studies part of formal education programs as well as continuing education programs for providers in psychiatry. In addition, these concepts should be added to peer support training. Providers are not typically made aware of social barriers of psychiatric disability, or even of disability civil and human rights and laws let alone how people in the system can access their rights as disabled people. Teaching the providers about the social, civil and human rights models of disability will help open the doors to greater self-determination for service users. These education programs would be most effective if taught by or with people who have psychiatric disabilities.

Lastly, the Recovery Model should be reframed so that it begins from the position that all disability, including psychiatric disability, is a normal part of the human experience. When services begin from this position, there is a greater tendency to consider the person's perspective and to look at the fit between the person's impairment and the environment in which they want to live, play and work. The process of reframing the recovery model could begin with a review of EBPs to determine how they might be changed to account for social barriers. For example, WRAP might include a section that intentionally addresses how to identify and manage the social barriers to participation. There might also be a section where the person learns about their rights and develops a

plan to participate in social activism in some way. The power that words, hold to form our understanding about disability is important to consider. An article modeled after Linton's chapter on Reassigning Meaning would be a valuable addition to the literature on Mad Studies. This study suggests that the words used in the Recovery literature are often defined differently by those in power which may be one reason why the model has not been as effective at shifting power and decision making as was envisioned.

#### G. **Further Research**

The results of this study suggest several next steps in advancing research in this area. There is a need to research the effectiveness of a program, specifically designed to introduce disability and mad studies concepts to people providing and seeking psychiatric services as a way of removing the barriers to empowerment for people with psychiatric disabilities. Adapting the Stepping Stone program to reflect the results of this study could be a first step. Once a program is developed it would be valuable to implement it with a larger group of service users and providers in a community mental health setting. A more formal measure of self-determination could be used to assess if there is a shift in the power structure and to determine what is most effective for supporting service users, so they can feel more self-directed. Research is needed to determine the impact of overcoming recovery stories and to explore the impact of restructuring to reflect more on disability identity and culture. This study also suggests that service users are interested in participating in research projects and with coaching could take a larger role in the production of knowledge. Lastly, this study suggest that participatory action research may be one way to increase the credibility and validity of people who identify with

psychiatric labels. Future research could bring service users voices into the project earlier, when the project is first being conceptualized, to be sure the outcome of the research is of most value to them.

## **APPENDICES**

## Appendix A

### Initial Interview Guide

1. Thresholds states that they provide recovery services. When you hear the term recovery what comes to mind?
  - a. How does Thresholds support recovery in day-to-day activities?
  - b. How do peer support services fit into the Thresholds model
  - c. Would you describe services as Person-Driven? (get at strength-based, responsibility and Respect aspects of recovery here).
2. Do the members of Thresholds have a sense of self-determination?
  - a. What supports or gets in the way of members self-determination?
  - b. What would get in the way of motivation for people in recovery?
  - c. What might keep people from exercising autonomy in their daily life?
3. What is your understanding of the Williams Consent Decree?
  - a. Do you believe people have a right to live in the community?
  - b. Is there any reason that people should remain in nursing homes or other institutions?
  - c. Do you believe that people have human rights?
  - d. Is living in the community a human right?
4. In the Thresholds program there are service providers and service users, and some people fall into both categories.
  - a. What do you use as the role of the providers?
  - b. Do service users have a role in the program and in recovery? If so, what?
  - c. Describe the relationship between providers and users? How do peer providers fit into this relationship?
5. What do you find most helpful for service users in the Thresholds program for people moving out of the nursing home?
  - a. Is there anything you would change and add?
  - b. Describe what the services would look like if they were ideal in your mind.
6. What would be important to include in a 10 week curriculum intended to help people with psychosocial disabilities be successful when they move into the community after living in a nursing home or institution?

## **Appendix B**

### **Prompts for Reflection Cycle Focus Groups**

#### **Week 1 Reflection Group**

After explanation of CI Process:

1. What are your preliminary thoughts about the Stepping Stones program related to the task of moving people out of nursing homes and the support systems in place here at Thresholds in Kankakee.
2. How would you describe our collaborative inquiry group?
  - a. What would you say are the relationships here
  - b. What might be the advantages of this work group for adapting this curriculum, what might be the barriers to being able to the process within this group?
  - c. What can we put in place to recognize any unanticipated barriers and address them in order to make sure everyone has an equal contribution to the process?
3. In addition to adapting the curriculum the CI process is meant to help adult learners develop insight into important concepts. What do you think we can learn about our selves through this process that might be helpful to other community mental health programs. What questions do we want to answer?

#### **Reflection Group Cycles 2-4**

1. Review the Previous Action Cycle discussion. Does anyone see anything they disagree with, want to clarify or add?
2. What do you think you learned from participating in the action cycle on \_\_\_\_\_? What do you think were your underlying assumptions?
3. What is the importance of the topic in this action cycle? How will it impact your participation in the user/provider relationship going forward?
4. Do you think there are barriers to shifting power between users and providers (assuming this is identified?).

#### **Reflection Group Cycle 5**



### Appendix B (continued)

When we met for the interview way back in September I asked you a number of questions and we have had some really important discussions as a group. I am going back to review some of those questions tonight.

1. First of all one of the things I asked you about was recovery and the process of recovery. Let's start tonight by talking about some of the things that you have considered about recovery since that first interview? How are you thinking about recovery and about person driven services after our discussions over the study period?

\*Considering people with the most needs, would you consider person-driven services any differently than before?

2. What about self-determination? Do you think about this differently? What do you see as barriers to self-determination?
3. The big question. What does it mean to have a disability?
4. Give everything we have talked about tell me what you think are human rights? How do people with emotional impairments achieve real human rights – regardless of how well they function?
5. What is the most important thing you have learned throughout this project?
6. Has anything changed for you – either in how you interact with each other, with other providers, with other service users? Have you talked with others about what you have learned?
7. What do you think others need to know? Who are others – providers, peers, community, police, policy makers? From the modules we studied? How might we create our new set of modules, what would be in them?
8. So What, Now What???

## Appendix C

### Group Plans for Action Groups 2, 4, 6, 8 and 10

#### **Plan for Action Group 2: Reframing Disability** **October 12, 2016**

Will be in room with a white board or flip chart. Will have a TV with a DVD player and access to the internet to watch TED talks and video.

Begin:

Review guidelines for discussion and discuss if there are questions.

Begin with word association game. They will write first thing that comes to their mind for the following.

Psychiatry  
Imbalance  
Survivor  
Disability  
Non-compliance  
Independence  
Madness

Once everyone has their response have them pair up and talk about them. Then share their discussions and thoughts with the group. Could write down some of the responses. Review one of the tenets of the lesson today – the power of language to construct something.

**Write down key words that come up in discussion.**

2 Questions: Again, jot down your answer. Then talk with a different partner. How is *Normal* determined? What had to be defined before the determination of normal could be made?

Begin the module review:

Initial thoughts?

What is your understanding of the two models talked about in the module? Medical Model vs Social model? Provide copies of pictures to clarify – could use white board too.

Go back to words from early and see what words are medical model – are any associated with social model?

What is the value of the medical model? Is there harm?

## Appendix C (continued)

**Read passage from McGruder on eliminating symptoms = eliminating history and identity.**

Watch the Longden Video and talk about when the voices got “Bad” and “Mad.”

**Review the clips from Billy (Chapter 2, 5 and 9. Especially 5 and 9.**

Get initial response – talk about disability as bad and sad – what are examples in society that indicate that disability is “bad and sad.” Is this really true? How does mental illness compare?

**Discussion questions from the session** – but then add can you see their point from the perspective of those with psychiatric disabilities?

Is there value to reframing to the social model?

Review the Credo handout and possibly watch the video

<https://www.youtube.com/watch?v=wunHDfZFxXw>

Is there a way to make it more applicable to people with psychiatric disability?

**Potential activities:**

**How does this social model apply to you?**

**Chalk talk** – What are some reasons that people ended up in institutions? Use activity on 1-15.

What is disabling for people with mental illness? List on the board. Talk about societal attitudes – use the Cole Ad to talk about how ads like this expect that people reading it have a certain set of beliefs. Again – look back at some of the words from the beginning to compare the new list.

Discussion question:

How does the Recovery Model fit into this description? –

Activity 1.4 talks about disability Pride. Joy in the film is one person who is taking pride in having a disability. Thoughts? What about taking pride in who you are with a mental illness? Some people call it Mad Pride. Reclaiming madness as a way of “being in the world” may be a way to move beyond the current attempts to decrease stigma.

You tube video on Self-Labeling

<https://www.youtube.com/watch?v=pxbw7dDMX60>

Potential videos and websites for discussion

The Voices in my Head – Eleanor Longden

[https://www.ted.com/talks/eleanor\\_longden\\_the\\_voices\\_in\\_my\\_head?language=en](https://www.ted.com/talks/eleanor_longden_the_voices_in_my_head?language=en)

Stella Young – Inspiration Porn

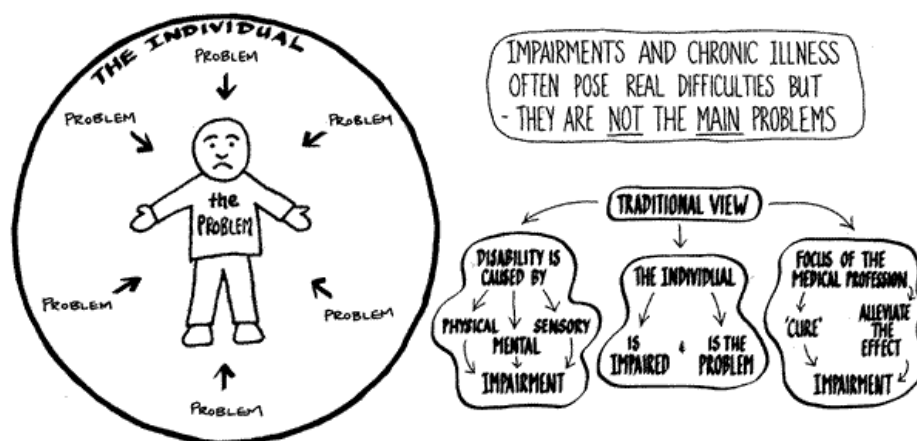
## Appendix C (continued)

[https://www.ted.com/talks/stella\\_young\\_i\\_m\\_not\\_your\\_inspiration\\_thank\\_you\\_very\\_much?language=en](https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much?language=en)

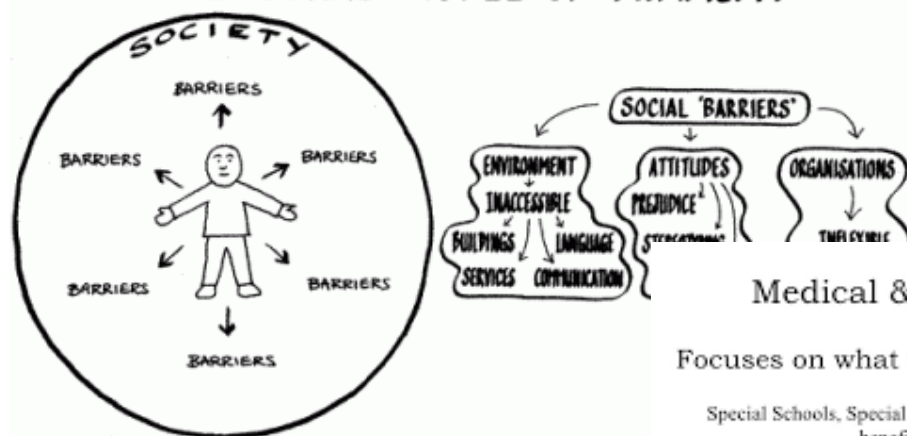
Maysoon Zayed – 99 Problems

[https://www.ted.com/talks/maysoon\\_zayed\\_i\\_got\\_99\\_problems\\_palsy\\_is\\_just\\_one?language=en](https://www.ted.com/talks/maysoon_zayed_i_got_99_problems_palsy_is_just_one?language=en)

### THE MEDICAL MODEL OF DISABILITY



### THE SOCIAL MODEL OF DISABILITY



Medical & Charity Model



Focuses on what is wrong with the person

Special Schools, Special vans and Rehabilitation and Passive beneficiaries of Charity



## Appendix C (continued)

### **Plan for Action Group 4: Disability Rights History, Legislation and Resources** **November 10, 2016**

Begin with a check in since last group – Some of the things I am learning from this process (include discussion from presentation power point). Quick review of Medical vs Social model. Talk about Human and Civil Rights models briefly

Have group brainstorm barriers in their small groups (groups of three). Remind them to consider all the levels of barriers.

Use a flip chart and sort them under Individual, Environment and System barriers.

**Discussion question** – How do we problem solve these barriers? – What has been the traditional way to problem solve barriers for people with psychiatric disabilities? ???- Have people with Psych Dis demanded their rights as humans? What has stopped people with psychiatric disabilities from demanding their rights as people?

#### **RISK Taking...**

**Word association game:** Risk, Safety, Health Maintenance, Nursing Homes.

What does risk-taking mean? Are people with psychiatric disabilities allowed to take risks? What does that have to do with nursing homes? Taking meds? What keeps people from taking risks?

(Pg 3-23 - Do we want to touch on the risk scenerios? If we were using this module to teach people who are moving out of Bourbonnais or Kankakee terrace how might we change them?)

Why is this important to legislation?

Have small groups sort out the cards – three sets of cards with legislation on them.

**Question: What legislation assures your right to community living?** Allow the group to talk about the cards. Then read off the items 1-8 and have the groups place the legislation on the number they think the legislation refers to.

Need three sets of cards with legislation and three pieces of paper with 8 blocks for sorting. Make copies of pgs 3-8 and 3-7 for quiz.

Open book to 3-9 – Fact Sheet on Section 504. Watch film. ( ??? )

<https://www.youtube.com/watch?v=SyWcCuVta7M>

Review History of ADA and look at sheet page 3-12 in manual.

Discussion: These are what are considered civil rights legislation – the disability civil rights act. Have you considered living in the community a civil right? Do people with psychiatric disabilities experience discrimination?

### Appendix C (continued)

Watch video with Tom Harkin and Kathy Martinez

Kathy Martinez – Disabilities and impact of the 504 sit-in

<https://www.youtube.com/watch?v=zHtmARooVEs>

Disabilities ADA – Tom Harkin

<https://www.youtube.com/watch?v=CNm48...>

Questions:

What did you learn from watching the videos?

Was there any part that really struck you?

Have you had experiences related to the ADA? Have you see people violating or abiding by this law?

Knowing the ADA, how can you practice your rights in daily life?

Go back to the chart from the beginning – talk about some of the solutions, action steps, etc.

What is Olmstead??

The manual talks about an Act called the Community Choice – this was actually abandoned in 2009 and included in the ACA. Now called the Community First Choice.

#### **Turn to the page on Community Choice Act**

Feds give states a 6% increase in federal matching funds for programs and services used for community-based long-term care (Medicaid and other matching programs). In order to qualify states must show they are spending more than 58% of the money earmarked for long term care on community-based services rather than nursing homes and institutions. Illinois has not qualified for this match – you can see the advantage since community based care is cheaper – money goes a lot further once the community programs are established.

Sooo

WHY AREN'T ALL PEOPLE SERVED IN THE COMMUNITY? In the interviews many people identified people who they thought needed to stay in the nursing home. Based on these laws, is there another option? How do we get people to see the advantage of having a PA or other attendant services in the community to help them develop the routines and skills they need, or just to help them with the tasks that are difficulty for them? (Downton Abby has people helping them get dressed...).

### Appendix C (continued)

Handout on the Ugly Laws...

Current bills related to mental health – hand out copies and discuss in small groups before big discussion.

Other laws related to mental health?? Gun laws, etc.

Mental health policy has gone back and forth from incarceration, possession, and beating the devil out of people to moral treatment, compassion and inclusion for a long time. In the end institutionalization has been the norm. What do you think needs to be done to change the system.

Would people be interested in taking pictures of things they think perpetuate stigma, exclusion and other systematic and environmental things that perpetuate exclusion for people with psych disability? Also could be things that are more inclusive??

**December 6, 2016**

#### **Plan for Action Focus Group 6 – Housing and Transportation, Social Networking and Finance**

Begin with questions or general thoughts about the three modules. What were some of the things you were thinking about when you were reading and thinking about the modules?

Begin with Module 4 – **Housing and Transportation.**

**Take the quiz** – as pairs – and talk about your experiences with housing? Did you see any discriminatory procedures – what do those look like for people with psychiatric disability? Sometimes for physical disability it is obvious – stairs etc. Need to type out questions and copy.

Question – the module talks about reasonable accommodations. What might that be for people with psychiatric disabilities??

\*\* Provide handouts? Not sure which ones yet... Probably speaking out – and the psych one that looks at the fact that people have physical disability as well as psych but it is ignored – this is not right.

How does the city here provide transportation? Do you have a right to protest the decrease in access to things like church – Ever notice everything revolves around work as if that is the only thing important.

## Appendix C (continued)

### Touch on Module 7 – **Finance**

The most intriguing thing in this discussion is the fact that finance (access to services, or not) revolves around work. Does everyone want to work? Are there other occupations of value??? When is work accessible for people with psychiatric disabilities? Not physical accessibility? Do we fight for the right to have access to work that is manageable when you only have so many spoons...??

SOCIAL NETWORKING – this is probably the key aspect for these modules.

Chalk talk – what sorts of support do we need in our everyday life? People who... When you are going to build this network, what are the barriers? Does this create disability?

Billy – first part and the part on finding the community.

The module talks about communication – including asking for help. What are some of the issues with asking for help for the psychiatric community? Thoughts?? Challenges?? What could be done different?

\*\*\* Part of building the network is asking for help – not just for medical or psychiatric reasons, for help getting to the store, or fixing the computer, or maybe a neighbor to help care for the cat when you go away... Networks are based on give and take – how many of you felt like you were in a situation where you were more the recipient of help and had little opportunity to help others? What is the result of that for people? Do you think people with psychiatric disabilities could maybe have PA's like people with physical disabilities? How do we help people with negotiating that relationship – what stands in the way.

Question – are people fearful of asking for help because they don't want to appear as if there is something wrong with them? This is a redefinition of independence – maybe to be independent is to manage the help you have in your life...

Let's create a meme...! ☺. What would the picture be? What would we say?

Communication also means speaking up to ??? (landlords, transport people, helpers, service providers, doctors, psychiatrists). Are there specific issues for people with psychiatric disability in these situations. What are some things that discourage people from speaking up. How do we address that?

There is a great discussion about preparing to meet with your doctor. What should people know about how to do this – what should be in the manual specific to psychiatrists?



### Appendix C (continued)

How have mental health services impacted the ability or desire of people with psychiatric disability to stand up for their rights?

Break into small groups. – Talk about the section on community.

Define community

What does it mean to be a part of a community?

How do you choose what communities you want to belong to?

What do you think is a “disability community?” Does Thresholds fit this definition? Could it???

\*\*\*\*Before the discussion for above questions

#### **Do the chalk talk Inclusion vs Belonging**

How might you as a group create a disability community? What would be your goal as a group given everything we have discussed so far in this program?

For this week I would like you to pair up with someone and create an action plan related to standing up for your rights – PROVIDE FORM.

#### **Plan for Action Group 8**

**Date: January 13, 2017**

Begin with a review of the themes from the first couple groups. Discuss the things people said in the groups – how are you thinking differently than before?

Discuss expectations of people with disabilities? What are the expectation of people with psychiatric disabilities? Is there a difference?

***Word Association game – Write down, then discuss in small groups.***

Overcoming

Inspiration

Play the video of Richie the race car engineer with no arms. Discuss the words in groups again – then together in connection with what they see on the film.

Introduce the articles – they can look at the titles, maybe look through it a little.

Are people with psychiatric disabilities held to overcoming narratives? How do these narratives contribute to stigma? How do inspiration stories contribute to stigma?

### Appendix C (continued)

Can recovery stories border on overcoming? What might be a better way to approach talking about recovery that allows for acceptance of difference, teaches people that being different is okay? We had a discussion about normal in the first action group – and the need to construct normal by identifying what is abnormal.

**Stigma** – Look through the comments made by group members on stigma. What are some of the approaches to changing stigma? Research shows that despite these approaches little has changed.

Other thoughts about the comments on the sheet.

REVIEW of models

SHEET OF PAPER – Put mental illness (medical model) on one side and psychiatric disability (social model) on the other and list advantages and disadvantages.

Break for food

#### **Review modules**

Module 9 – Long term care

**Long term care** – Discuss options for Long Term Care for people with psychiatric disabilities.

Nursing home

Home and Community Care

What else??

Do they support self-determination?

Look at Personal Assistant, having support in the home, Accessibility, adaptive equipment – etc – look at options page 9-7.

What if the people moving out of the nursing home identified what services they need?

What are the barriers to that? How do we change that process?

Module 10 – Health living

There is a huge issue with food and food labels. I have some real fundamental issues with the information on food and food nutrition in the book. Even the heart association has backed off a number of these things we have thought were “healthy.”

For example - we have been taught that low fat is healthy. Pull a few things from the cabinets.

### Appendix C (continued)

Is there a rise in processed foods? Name 10 foods you ate in the last couple days? How many have corn products? So how do you eat health on a small budget when boxed foods are full of artificial and processed ingredients. You can eat better...

Physical activity – How can people be more physically active – what gets in the way? As you get older you do need to strengthen muscles as well as raise your heart rate? How does smoking interfere?

Social and community participation.

Thoughts on the idea of informed (mitigated) risk? How does this idea fit into self-determination? Do people have a right to take risks. In the module they are referring to the risks associated with physical disability. Are there risks for people with psychiatric disability?

How can providers support access to risk? What does it mean to mitigate risk?

Discuss need to meet next week

Do people have things written in their notebooks – Can I take them for the week?

#### **Plan for Action group 10,** **Feb. 15, 2017**

#### **Begin with everyone reading this discussion from the December Focus Group on Homelessness**

With this cold weather upon us. I keep on hearing this wind whipping up behind this. Um what can we do in our area for the homeless? I advocate for the homeless quite a bit, since I had been one a couple times. Um, you know, we don't have enough homeless shelters in this area.

We don't – no

And my heart goes out to them. I am not going to bring any into my own apartment though, for my own safety

Chuckles - Well bring them to Jim's- (Everyone laughs)

I am not going to bring them to Jim's either - for his own safety either. But we don't have adequate shelters in this area and we have a large homeless population in this area.

Larger than what people think.

### Appendix C (continued)

People don't realize it, yeah.

yeah

It is such a toss up because... So I am going to say something that's, that a..

People in this area don't care, I don't think..

Its not that, it's..

Yeah, I mean I think there are some people probably who don't care. I think there are people who care but feel helpless...

There's stigma too I think.

There is definitely stigma and actually...

I caught myself doing that, I was like..

just said for her own safety she wouldn't let anyone in so there's an assumption there...

well no, I can't but, my heart is still out there – I've been there.

What is sort of interesting to me, and this was something that sort of struck me is that.. so often these organizations are run by poverty, right? – sorry, by charities. And um, and here's another sort of interesting conundrum that the disability community puts out is that as long as there are charities that are taking care of these things then the government doesn't have to.

(There are inaudible comments because TL is coming in and settling – completely missed the point.)

It is really, again we are faced with this - whose responsibility is it to be sure that people have their human rights.

Basic rights, yeah.

I understand.

Who funds the Salvation Army?

They are self-funding. They ah, take donations. It can be cash, it could be a car, it can be clothes, anything. And it's given to them and they sort through it and then they put it in their thrift stores and they sell it. That's how they make their money.

I think they're selling things overseas like I think they can make money, just like

Goodwill

### Appendix C (continued)

Yeah they are a top 500 company

Yeah they're all over the world. They are a self-supported company.

So the Salvation Army is a fortune 500

Yeah

Generally speaking the issue is the charities, whereas government policy will cover everybody the charities only cover the people local, but it allows the government to ah..

So they put them in the hospital for a couple of days.

Yeah that's what happens a lot of times too, yeah

Which is so silly right? Because it is so much more expensive.

Exactly

Than to provide services in the community.

But, but they put them in the hospital, they don't have insurance, and then they're billed for the thing and then again we go "but I have no money."

It's a cycle

it's a cycle

it's a vicious cycle

so you've got the hospitals where are not getting paid for these and they're putting people because they have no place to go. And it all ends up back on the hospital and the people who are in poverty.

Several agree.

Yeah. Pause. I had the conversation, cause for some reason this homelessness thing kept coming up and up, not just in my home situation but at the church I was at, I was speaking to somebody and he was saying, he was a leader in the church, he was saying well, he was talking about a shelter, one of the few shelters we have (local shelter). It's all men. And he was saying, I know the guy who runs it too, pastor E. He's very tough, he is very strict. And he was saying, "yeah, he's got to be that way because most of the homeless people that come in there, they are homeless because, he was saying they are rebellious. They just choose to be homeless. Yeah you can give them a place to live but down the road their going to end up back on the streets again.

### Appendix C (continued)

yeah and I know a guy who is homeless, who has been given apartment where the rents paid and the furniture is free and the minute he is responsible for paying the rent or the electric bill, he just walks away. He just walks away. My money doesn't need to be spent that way.

So I would say though, that that's a very small percentage.

yeah, Oh, I but I mean..

There are those like that way though.

Well you wonder if there's not another alternative. Like what's the alternative?

Is it okay for people to be homeless if they choose to be?

There are some. If they choose to be. There are some people who want to stay homeless, there are those, I've ran into those people. They choose that, that is their life. Then there are those who are not by choice, by circumstances.

yeah I think statistically it does show that the majority of homeless, the majority have some kind of illness or a mental illness or um, a lot of times it could be drug problems or some kind of thing going on like that. But yeah, I do think...

Which creates, begs the question are the supports in place? That those kinds of supports in place.

That is what I was going to say, that is the solution I think

that's where our continuum of care fits in, (KW and L – say right) which is really hard to get set up.

Cause a lot of people like that's a scary thing, stability. Like that is all they know is instability, that's what their comfort is. You give the stability they can't handle that you know.

Well it comes with a set of responsibilities and rules that they're not prepared to do that.

Yeah, they're not prepared, it's just not something familiar to them.

right.

Well is homelessness just a symptom of a bunch of other root causes? Like we said substance addiction you know? Part of that is responsibility, accountability because there's a price that comes you know with having a degree of freedom and responsibility. I

### Appendix C (continued)

mean to some people you know just aren't there, I guess. I mean freedom comes with a price basically and some people just don't have a certain level of accountability and responsibility. Um, ***Poor money management skills, lack of ability to prioritize things.***

Thoughts???

*(is this different in the non mh world though? What's the difference??? Lots of people have poor money management and lack of ability to prioritize things – they just have the means and resources to avoid the dire consequences.)*

***There is a lot of discussion about homelessness here – about their intentions, about their needs. Although at least one person claims to be homeless, we are not really including their input here...***

***Is this an “ablest” approach. Because we are not homeless we know the reasons they are...?***

**Once this discussion is done introduce the idea of Marginalization. We have discussed the idea of oppression and marginalization for people who have psych disabilities. What does it mean to be marginalized?**

**Share picture that represents marginalized people. Concentric circles. Have the group break into smaller groups and talk about the image. Who is in what circles, where do they see themselves as falling. We spoke of oppression last time, where do oppressed people fall?**



Put this Image on the back...

*People who live this every day see that others don't. This is the privilege of being on the outside (marginalized people with disability). This is your ability to see the challenges of the normative population. How do we use this “marginalized” vision or position to start to inform*

*the ablest-minded community?*

**Introduce this conversation from the December Focus group.**

### Appendix C (continued)

Yeah, you know people, you know, labeling yourself disabled is probably the most disabling thing you could do.

Is it?

I don't know. The flip side is understanding your limitations is part of maturity too.

Exactly –

or the other scenario, is claiming you're not disabled...?

problematic...

denial?

denial and if you're not, if you're saying you're not disabled, you disabling yourself by not being able to use the helps and the tools and everything else out there that can get you to where you want to be.

Which brings me back to why is it bad to have a disability.

I don't think it is, I just don't anymore. I use to at one point, oh my word, but I just don't think so.

it's just gotten to be a way of life. You just learn to live with it.

**Talk about this conversation in light of what we have been discussing. How does personal Responsibility fit in. Have people identify things that are personal responsibilities related to mental illness. Use the board to highlight personal responsibility of managing the symptoms and choices around the symptoms. – What does that lead to.**

**Then highlight the issues with socially disabling (refer to the conversations from the last set of meetings – what else is “disabling”) – what could be different in society when it came to psychiatric disabilities. Think back to previous discussions about what is disabling.**



### Appendix C (continued)

**Would we need overcoming narratives if we had this type of situation? What might we talk about instead?**

**Play the SCOPE video on the Social Model of Disability.**

**<https://www.youtube.com/watch?v=0e24rfTZ2CQ>**

*What if we replace the word disability with impairment. There is personal responsibility to manage the impairment – that society disables with lack of supports. So people have some responsibility for themselves but it is a combo of impairments and life situation that mean they don't have the same internal (or external resources) to do the things they need and want to do)*

**Choose words! What should we say when referring to this situation.**

**Put words on cards for sorting.**

**I, am, have, a, disability, mental illness, mentally ill, impairment, impaired, sick, special, crazy, capable, challenged, disabled, by Society, by, brain disorder, work, with, deal, with, a, person, human, rights, have, symptoms, different, thoughts, moods, can, be,**

**Put up the words on sticky notes and rearrange them to form the statement we like – One we could own as a group to reclaim humanity as people who are disabled by society???**

### **BREAK**

Three modules for computers and technology. First is basics (turning it on, searching, using email), second is adaptations and the third is social networking and finding information.

### Appendix C (continued)

**What are the benefits of using computers? What are your challenges? The world is using computers. How would having access benefit you as a person with a psych disability? Would SMART phones help?**

Watch Video – this is a video about fixing a school. But while watching think about what she did to change a situation that seemed unchangeable. How might we think about what she said for our situation – our being the situation we find ourselves in as service users and providers in the mental health system?????

So What, Now What TED talk –

<https://www.google.com/search?q=tet+so+what+now+what&oq=TED+So+wha&aqs=chrome.0.0j69i57j0l2.3769j1j4&sourceid=chrome&ie=UTF-8>

### Final discussion

**Reminder that next week is the last session. Please bring notebooks. I will return them to you. Please think about what you learned, what was most important to you. How you think this might have an impact. Ideas for “now what.**

## Appendix D

### UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

#### Approval Notice Continuing Review

June 20, 2017

Lisa Mary Mahaffey, MOT  
Disability and Human Development  
1919 W. Taylor  
M/C 811  
Chicago, IL 60612  
Phone: (312) 996-3051 / Fax: (312) 413-0256

**RE: Protocol # 2016-0336**  
**“Fostering Self-Determination as a Means to Recovery”**

Dear Ms. Mahaffey:

Your Continuing Review was reviewed and approved by the Expedited review process on June 18, 2017. You may now continue your research.

Please note the following information about your approved research protocol:

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**Please note that this research did not have Institutional Review Board (IRB) approval from midnight June 02, 2017 until June 18, 2017. Any research activities conducted during this time were done without IRB approval and were not compliant with the UICs human subject protection policies, The Belmont Report, UICs Assurance awarded by the Office for Human Research Protections (OHRP) at HHS, and with the federal regulations for the protection of human research subjects, 45 CFR 46.**

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**Protocol Approval Period:**

June 18, 2017 - June 18, 2018

**Approved Subject Enrollment #:**

12 (0 @ UIC, 12 @ Thresholds  
Psychiatric Rehabilitation Centers; closed to  
enrollment)

**Performance Sites:**

a) UIC, b) Thresholds  
Psychiatric Rehabilitation Centers  
None

**Sponsor:****Research Protocol(s):**

a) Protocol: Self-Determination; Version 1; 03/23/2016

**Recruitment Material(s):**

a) N/A- Closed to enrollment

**Informed Consent(s):**

a) N/A- Closed to enrollment

**Additional Determinations for Research Involving Minors:**

These determinations have not been made for this study since it has not been approved for enrollment of minors.

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
06/09/2017	Continuing Review	Expedited	06/18/2017	Approved

Please remember to:

→ Use your **research protocol number** (2016-0336) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance,

**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

(<http://research.uic.edu/irb/investigators-research-staff/investigator-responsibilities>)

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 413-0241. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,  
Ibraheem Oguntade  
IRB Coordinator, IRB #2  
Office for the Protection of Research

Subjects

Enclosure(s): None

cc: Tamar Heller, Disability and Human Development, M/C 626  
Yolanda Suarez-Balcazar (Faculty Advisor), Disability and Human Development,  
M/C 811

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## VITA

**MARY ELIZABETH (LISA) MAHAFFEY**  
**1611 SIERRA HIGHLANDS DRIVE**  
**PLAINFIELD, ILLINOIS 60586**

Phone: 815-529-1547

[lisaotr84@gmail.com](mailto:lisaotr84@gmail.com)

### ACADEMIC BACKGROUND

PhD Candidate. **PhD Disability Studies Program**, University of Illinois at Chicago

1992 **Master of Science Degree Occupational Therapy**, University of Illinois at Chicago

1985 **Bachelor of Science Degree Occupational Therapy**, University of Wisconsin-Madison

### FURTHER TRAINING

2011 Assessment of Motor and Process Skills Training and Calibration, Chicago, IL

2011 The Art and Science Behind Writing Effective Multiple Choice Items, NBCOT workshop, University Park, IL

2009 Scholarship of Teaching and Learning, Downers Grove, IL September 2009

2008 Crucial Conversations, Naperville, IL November

2005 How Does Your Engine Run? The Alert Program for Self-Regulation. Sherry Shellenberger and Mary Sue Williams, Instructors

2004 Introduction to Dementia, AOTA Online Course, Mary Corcoran Instructor

1999 Facilitating Client Centered Reasoning, College of DuPage Department of OT

1997 Institute on Teaching Techniques, Preparing Lectures and Exam Questions  
AOTA Conference, Orlando, FL 1997

### PROFESSIONAL EXPERIENCE

2009 – Present **Associate Professor**, Midwestern University Department of Occupational Therapy

- Teach courses including Theory, conditions, Occupational Roles and Participation.
- Serve on academic committee
- Carry an advisory load
- Faculty advisor to the Student Occupational Therapy Association

- Serving on the Diversity Committee
- Level I Community Fieldwork supervisor with Thresholds, supervising students working with people who have recently moved out of nursing homes into community living. Consultation and student supervision for experiential learning program - Lutherbrook Academy Therapeutic Day High School

2009 – Present, **Occupational Therapy Consultant** Linden Oaks Hospital at Edward Naperville, IL

- Consult monthly with COTA
- Assist with development of multiple programs
- Develop and present staff in-services
- Development and implementation of sensory cart and tools for reduction of self-harm and restraints

2013 - 2016 **Consultant**, Thresholds Community Mental Health, Sandler Center.

2003 - 2009 **Occupational Therapist**, Linden Oaks Hospital and Edward Academy Therapeutic Day Elementary School, Naperville, IL

1995 - 2003 **OTR**, Presence St. Joseph Medical Center, Joliet IL in Adult, Adolescent and Pediatric Mental Health

1992 - 1994 **OTR Program Coordinator**, Silver Cross Hospital Joliet, IL, Adult Mental Health

1987 - 1988 **Research Assistant** for Gary Kielhofner at University of Illinois at Chicago Occupational Therapy Department.

1985 - 1995 **OTR**, Full time/Part time/Call Staff Hinsdale Hospital, Hinsdale, IL, Adult and Adolescent Mental Health

1991 - 1992 **OTR, Consultant** Comprehensive Therapeutics Northbrook, IL, consultant to Occupational Rehab Programs in Intermediate Care Facilities for the MI

## TEACHING:

### University Curricula:

2016-2017 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (3 credits)
- OTHE 667 Psychosocial Practice – co-instructor (4 credits)
- OTHE 620 Theoretical Constructs II (3 credits)
- OTHE 637 Group Process (3 credits)

2015-2016 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (3 credits)
- OTHE 667 Psychosocial Practice – co-instructor (4 credits)
- OTHE 536 Fieldwork I-A Provided clinical supervision in a Community fieldwork experience for 14 students.
- OTHE 620 Theoretical Constructs II (3 credits)

#### 2014-2015 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (3 credits)
- OTHE 667 Psychosocial Practice – co-instructor (4 credits)
- OTHE 536 Fieldwork I-A Provided clinical supervision in a Community fieldwork experience for 8 students.
- OTHE 620 Theoretical Constructs II (3 credits)

#### 2013 – 2014 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (3 credits)
- OTHE 667 Psychosocial Practice – co-instructor (4 credits)
- OTHE 536 Fieldwork I-A Provided clinical supervision in a Community fieldwork experience for 15 students.
- OTHE 620 Theoretical Constructs II (3 credits)

#### 2012 – 2013 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (2 credits)
- OTHE 667 Psychosocial Practice – Lead instructor (4 credits)
- OTHE 620 Theoretical Constructs II (3 credits)
- OTHE 536 Fieldwork I-A Provided clinical supervision for community fieldwork for 4 students

#### 2011 – 2012 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (2 credits)
- OTHE 667 Psychosocial Practice – Co-instructor (4 credits)
- OTHE 620 Theoretical Constructs II (3 credits)
- OTHE 535 OT Group Process (2 credits)

#### 2010 – 2012 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 560 Occupational Roles and Participation (2 credits)
- OTHE 620 Theoretical Constructs II (3 credits)
- OTHE 626 Human Conditions IV (3 credits)
- OTHE 629 OT Group Process (2 credits)
- Served as faculty mentor with 18 students for Experiential Learning with Adolescents in a therapeutic day school program

#### 2009 – 2010 Midwestern University Occupational Therapy Program

- OTHE 505 Human Conditions I (3 credits)
- OTHE 540 OT Analysis I (3 credits)
- OTHE 560 Occupational Roles and Participation (2 credits)

- OTHE 620 Theoretical Constructs II (3 credits)
- OTHE 629 OT Group Process (2 credits)
- OTHE 626 Human Conditions IV (3 credits)
- Served as faculty mentor for 12 students for Experiential learning in a pediatric therapeutic day school program.

#### 2008 - 2009 Midwestern Occupational Therapy Program

- OTHE 540 Analysis I – Adjunct instructor (3 credits)
- OTHE 541 Analysis III (3 credits)
- OTHE 626 Human Conditions IV (3 credits)
- OTHE 620 Theoretical Constructs II (3 credits)

#### 2007 – 2008 Midwestern University Occupational Therapy Program

- OTHE 540 Analysis I – Adjunct Instructor (3 credits)

## PRESENTATIONS

### Professional/Peer reviewed

- |      |  |
|------|--|
| 2017 | <b>Make the Occupational Profile Vibrant: Extend the Findings Beyond the Clinic.</b> Illinois Occupational Therapy Association Annual Conference, Normal, IL.  |
| 2017 | <b>Why Occupation?</b> Illinois Occupational Therapy Association Annual Conference, Normal, IL.  |
| 2017 | <b>Join the Mental Health Community of Practice.</b> Illinois Occupational Therapy Association Annual Conference, Normal, IL.  |
| 2016 | <b>Fostering Self-determination: Preliminary Results of an Action Research Project that Considers A Disability Studies Approach to Supporting People with Psychiatric Disabilities.</b> Illinois Occupational Therapy Association Annual Conference, Naperville, IL. |
| 2016 | <b>Findings from an Exploratory Pilot Study: Catalysts and Barriers to incorporating Social Model and Social Justice Issues into Practice.</b> Illinois Occupational Therapy Association Annual Conference, Naperville, IL.  |
| 2016 | <b>Shifting the Power Dynamic: Collaborating with the Disability Community to Promote a More Client-Centered Practice.</b> American Occupational Therapy Association Annual Conference, Chicago, IL  |
| 2016 | <b>MHSIS Annual program: Enabling Community Integration and Participation for Individuals with Psychosocial Disabilities.</b> American Occupational Therapy Association Annual Conference, Chicago, IL   |

- 2015 **Building your Occupation-Base Toolbox.** Illinois Occupational Therapy Association
- 2015 **Occupational Therapists as Disability Allies.** Illinois Occupational Therapy Association Conference, St. Charles, IL
- 2015 **Shifting the power dynamic: Collaborating with the disability Community to promote a more Client-Centered Practice.** American Occupational Therapy Association, Chicago, IL.
- 2015 **MHSIS Annual Program: Enabling Community Integration and Participation for Individuals with Psychosocial Disabilities.** American Occupational Therapy Association, Chicago, IL.
- 2014 **Enabling community Integration and Participation: An OT Workforce Call to Action.** Illinois Occupational Therapy Conference, Lisle, IL
- 2014 **The Occupational Therapy Practice Framework: Is there really evidence to support occupation as means and end in mental health practice.** Illinois Occupational Therapy Conference, Lisle, IL
- 2013 **Building a Mental Health Work Force. Panel Presentation.** Illinois Occupational Therapy Conference, Peoria IL
- 2013 **Using A Theoretical Model to Design Intervention in a Community Mental Health Program.** Illinois Occupational Therapy Conference, Peoria, IL
- 2013 **AOTA Talk About: Update on the Revisions of the Occupational Therapy Practice Framework.** Panel Presentation with the Commission on Practice, American Occupational Therapy Conference, San Diego, CA
- 2012 **AOTA Talk About: Revisions of the occupational Therapy Practice Framework.** Panel Presentation with the Commission on Practice. America Occupational Therapy Conference, Philadelphia, PA
- 2012 **Enabling Communication and Personhood for People with Dementia** Illinois Occupational Therapy Association CE presentation
- 2012 **Pediatric Mental Health: Theories and Interventions.** Co-presented with Anne Kiraly-Alvarez, Illinois Occupational Therapy State Conference
- 2010 **Mental Health Knowledge and Skills Paper: Conception, Content and Future** Illinois Occupational Therapy Association Conference
- 2010 **When Self-Injury and Eating Disorders Meet: Using Sensory Modulation Techniques—**Co-presented with Trish Jones-Bendel. Eating Disorders Conference, Skokie, IL
- 2009 **Implementing a Sensory Modulation Based Intervention Program to**



- Address Behaviors in an Acute Care Facility.** Illinois Occupational Therapy Association Conference
- 2009 **Using Occupation to Understand Behavior, Provide Individual and Population Based Care and Advocate to that People with Dementia can Live with Meaning and Purpose.** American Occupational Therapy Conference
- 2009 **Using Evidence in Program Development in Eating Disorders.** Midwest Dean's Conference, St. Ambrose University
- 2007 **Communication and Behavioral Analysis with the Older Adult with Dementia.** Illinois Occupational Therapy Conference 2007
- 2006 **Animal Assisted Therapy in Mental Health.** Illinois Occupational Therapy Association Conference
- 2006 **Do People Have to be oriented to be Happy?** Midwestern Geriatric Education Conference
- 2006 **Teaching Life Skills to the Eating Disordered Client.** Roundtable discussion AEDP Symposium
- 2001 **Developing a Student Program.** Illinois Occupational Therapy Association State Conference
- 1996 **Measuring Occupational Functioning.** American Occupational Therapy Association National Conference

**Invited Presentations:**

- 2016 **Why Occupation?** OT Month Presentation at Shirley Ryan Ability Labs. April 2017
- 2016 **Identifying our Distinct Value.** Presentation at RIC for the Leadership Counsel
- 2014 **Occupational Therapy Practice Framework.** Midwestern University Scholarship Lecture Series. Downers Grove, IL
- 2014 **Enabling Independence** Arden Courts CE program (also 2011 and 2009)
- 2011 **Enabling Independence:** Northern Illinois University Certification Program for non-physicians in Dementia
- 2010 **Analyzing Behavior and Communicating with the Person with Dementia.**  
OT Month presentation for Adventists Bolingbrook Hospital, Bolingbrook, IL

- 2009/10      **Sensory Modulation, Eating Disorders and Self-Harm.** Linden Oaks Hospital Conference on Eating Disorders
- 2008/09      **Sensory Modulation and the Sensory Room in Mental Health.** Linden Oaks Hospital
- 2008          **Keynote Address: Supporting Occupations and Creating Opportunities Through Advocacy.** Illinois Occupational Therapy Convention
- 2008          **Communication and Behavioral Analysis with the Older Adult With Dementia.** Illinois Department on Aging
- 2008          **Communicating with People who have dementia.** Guest speaker on Webcast – Journey through Alzheimer's. InTime TV, Chicago, IL
- 2007          **Communication and Behavioral Analysis with the Older Adult with Dementia,** AOTA Audio Insight Presentation
- 2007          **Geriatric Mental Health and Communication and Behavioral Analysis,** University of Illinois Certification for Non-Physician's in Geriatrics, Mental Health, Aging and Dementia.
- 2007          **Planning and Implementing Groups for Patients with Dementia.** Linden Oaks Hospital Geriatric Unit
- 2006          **Life Story Books.** Care with Finesse Series, Linden Oaks Hospital Geriatric Program
- 2005          **Exercise in Eating Disorder Program** Edward Hospital Professional Education
- 2004          **Bipolar Disorder.** Edward Hospital community presentation
- 1995          **Interventions with Clients with Dementia.** Illinois Occupational Therapy Association CE event. Willowbrook, IL
- 1995          **Interventions with clients with Dementia.** Provena St. Joseph Medical Center
- 1993          **Interventions with Clients with Substance Abuse and Personality Disorders.** Rush Presbyterian St. Luke Occupational Therapy Program

## SCHOLARLY ACTIVITIES

### Peer Reviewed Publications

- Mahaffey, L., & Januszewski, C., (in press). Chapter 30: The public policy environment. In Brown, C., Stoffel, V.C., & Munoz, J., (Eds.), *Occupational therapy in mental health: A vision for participation 2<sup>nd</sup> Ed.* Philadelphia, PA: F.A. Davis.
- Mahaffey, L & Dallis, J.,(in press). Chapter 42: The continuum of care: Supporting people through crisis to living in the community. In C. Brown, V.C. Stoffel, & J. Munoz, (Eds.), *Occupational therapy in mental health: A vision for participation*, 2<sup>nd</sup> ed. Philadelphia, PA: F.A. Davis.
- Sood, D., Fisher, G., Mahaffey L., Wong, S.R., Baum, C.,& Cada, E. (2017). Chapter 11: Occupation-focused models. In S.A. Dsouza, R. Galvaan & E. Ramugondo (Eds). *Concepts in occupational therapy: Understanding southern perspectives.* Manipal, India: Manipal University Press.
- Lee, D. & Mahaffey, L. (2017) Community living and integration. *Disability in American Life:An Encyclopedia of Concepts, Policies, and Controversies.* Santa Barbara, CA: ABC-CLIO, Inc.
- Mahaffey, L. (2017). Mental Health self-help and support group. *Disability in American Life: An Encyclopedia of Concepts, Policies, and Controversies.* Santa Barbara, CA: ABC-CLIO, Inc.
- Mahaffey, L., & Januszewski, C., (in press). Assessments Used with the Model of Human Occupation. In B. Hemphill-Pearson & C. Urish (Eds.). *Assessments in Occupational Therapy Mental Health*, Thorofare, NJ: Slack, Inc.
- Mahaffey, L., (in press). Occupational profile and interviewing in occupational therapy. In B.Hemphill-Pearson, & C. Urish, (Eds.). *Assessments in Occupational Therapy Mental Health*, Thorofare, NJ: Slack, Inc.
- Mahaffey, L., Burson, K., Januszewski, C., Pitts, D., & Preissner, K., (2015). Role for occupational therapy in community mental health: Using policy to advance scholarship of practice. *Occupational Therapy in Healthcare*, 29, 397 – 410.
- Mahaffey, L. (2015). Abigail. In S. Cahill & P. Bowyer (Eds.). *Cases in pediatric occupational therapy: Assessment and intervention.* Thorofare, NJ: Slack Inc.
- Mahaffey, L., (2014). Occupational identity and recovery for people with psychiatric disabilities. *Mental Health Special Interest Section Quarterly*, 37, 1-3.
- AOTA Commission on Practice (2014) *The occupational therapy practice framework, third edition.* Bethesda, MD: AOTA Press.
- Mahaffey, L (2013) Redressing health care and wellness inequality through occupational therapy, *OT Practice* 18,8.

- Mahaffey, L. (2013) Providing interventions through telehealth technology. *OT Practice*, 18,6.
- Mahaffey, L., & Coliani, D. (2012) The international classification of functioning, disability and health and the OT practice framework. *OT Practice*, 17, p. 7.
- Mahaffey, L. (2012) Chapter 14: Managing difficult groups. In J. O'Brien, & J. Solomon (Eds.) *Occupational and group analysis*. Philadelphia, PA: PA: FA Davis.
- Mahaffey, L. (2011) Community Mental Health Centers: Occupational therapy within the service team. *OT Practice*, 14, p. 20.
- Scott, J. B. & Mahaffey, L. (2011). Chapter 7: Occupational engagement of older adults with mental illness. In M.K. Scheinhotz, (Ed.) *Occupational therapy in mental health: Considerations for advanced practice*. Bethesda MD: AOTA Press.
- Mahaffey, L., & Holmquist, B., (2011). Chapter 41: Hospital based mental health care. In C. Brown, & V.C. Stoffel, (Eds.), *Occupational therapy in mental health: A vision for participation*. Philadelphia, PA: F.A. Davis.
- Mahaffey, L., (2009). Incorporating evidence in mental health practice: Articles from the AOTA mental health annotated bibliography project. *Mental Health Special Special Interest Quarterly*, 3 1-4.
- Mahaffey, L. (2009). Using theory and the therapeutic reasoning process to guide evaluation and intervention for the older adult with mental illness. OT Practice CE Article. *OT Practice*, 14, 37–42.
- Mahaffey, L. (2008). *Mental health in children and youth: The benefit and role of occupational therapy*. American Occupational Therapy Association Fact Sheets.
- Mahaffey, L. (2006). Building a mental health practice: Tradition and innovation in an acute care setting. *OT Practice*, 11, 14-18.
- Mallison, T., Mahaffey, L. & Kielhofner, G., (1998) The occupational performance history interview: Evidence for three underlying constructs of occupational adaptation. *Canadian Journal of Occupational Therapy*, 65, 219-228.
- LaPlante, D., & Gutkowski, L. (1995). A vocational program for acute psychiatry. *Mental Health Special Interest Section Newsletter* 15, 1-2.

## Thesis

- 1992 Reliability and Validity of the Occupational Performance History Interview, phase III. Master's Thesis completed in partial fulfillment of the Masters of Science in Occupational Therapy for the University of Illinois at Chicago.

## Research Activities

**Current**            **Fostering Self-Determination as a Means to Recovery.** A participatory action research project designed to bring mental health service users together with providers to develop a shared understanding of psychiatric disability and explore the impact to collaboration in care.

Occupational Therapy Needs of People with Psychiatric Disability who are Not Thriving After Institution-to-Community Transition.

## Grant Activity

**Active Grants**   **Project Title:** Tiered Occupational Therapy (TOT): Preparing Scholars to Work in School Mental Health.  
**Role:** Project Director  
**Amount:** 1.2 Million  
**Funding Source:** The United States Department of Education.  
**Funding Period:** 12/1/2015 – 11/30/2020

## PROFESSIONAL SERVICE

2014 to present	President of the Illinois Occupational Therapy Association
2013 to 2014	President-Elect of the Illinois Occupational Therapy Association
2012 to 2013	Member of the MWU University Diversity in Education Committee
2011 to 2014	Chair of the Occupational Therapy Department Academic Review Committee.
2012	Commission on Education Fieldwork task force to explore key documents in preparation for revising the Fieldwork Performance Evaluation for the American Occupational Therapy Association
2011 to 2012	Member of the MWU OT curriculum committee in preparation for the ACOTE accreditation review.
2011 to 2014	Member of the Commission on Practice for the American Occupational Therapy Association. Primary responsibility is to review official papers of the profession. This commission completed the five year review and third revision of the Occupational Therapy Practice Framework.
2009 to 2014	Director of Finance for the Illinois Occupational Therapy Association
2008 to 2009	Served on the Task Force developing the Mental Health Knowledge and Skills Paper for the American Occupational Therapy Association

2009 to Present	Faculty Advisor for the MWU Student OT Association. Received the Outstanding service leadership award 2011, 2012 and 2013.
2009 to Present	Faculty member of the Admission Committee.
2009 -2012	Member of the MWU Student Promotion and Graduation committee
2008	Served on the AOTA President's Task Force on Mental Health Practice
2006 to 2009	Chair of the Mental Health Special Interest Section for the American Occupational Therapy Association
2003 to 2004	Served on the Board of Directors for the College of DuPage Occupational Therapy Assistant program

### **PROFESSIONAL AWARDS**

- 2013 **American Occupational Therapy Roster of Fellows**
- 2009 **Beatrice Wade Award** for excellence in fieldwork education, University of Illinois Department of Occupational Therapy
- 2009 **Occupational Therapist of the Year** awarded by the Illinois Occupational Therapy Association
- 2008 **Keynote Address: ILOTA 2008 State Conference** – Supporting Occupations and Creating Opportunities through Advocacy

### **Professional Certifications:**

Illinois State License for Occupational Therapy #056.001382, obtained 1985

National Board for Certification in Occupational Therapy #AA430033 obtained 6/7/1985

Calibrated for the Assessment of Motor and Process Skills, completed 2011