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ServiceNet participatory action research program evaluation : a project based on an independent investigation at ServiceNet in Northampton, MA

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ServiceNet: Participatory Action
Research Program Evaluation

ABSTRACT

This research project sought to evaluate if program participants of ServiceNet's Mental Health Recovery Services (MHRS) feel supported to meet their self-defined needs and goals. These researchers were guided by the principles of Participatory Action Research (PAR) and facilitated three focus groups who designed a mixed-methods survey-tool to be distributed by ServiceNet Recovery Counselors. Twelve surveys were refused and returned unopened, 56 program participants received the survey envelopes and did not return them, and 34 surveys were returned completed (n=34).

Participants demonstrated high satisfaction around housing, transportation, personal growth, emotional support, feeling treated like a human being, medication information, staff-training, and connection to staff. Participants reported lowest levels of need fulfillment around feeling heard if they were unsatisfied with services and feeling informed about the human rights complaint process. Qualitative analysis reveals high levels of self-pathologizing attitudes, low levels of self-compassion, and low levels of hope. These researchers question if greater utilization of anti-oppressive frameworks and practices might reduce self-pathologizing perceptions and increase hope and self-compassion among ServiceNet program participants. These researchers propose some project structure changes, as well as changes in demographic data collection to enable regression analyses and compare levels of satisfaction and fulfillment between different demographic variables.

SERVICENET PARTICIPATORY ACTION RESEARCH

PROGRAM EVALUATION

A project based on an independent investigation at ServiceNet in Northampton, MA, submitted
in partial fulfillment of the requirements for the degree of Master of Social Work.

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CHAPTER I

Introduction

Since the 1980's, there has been increasing attention paid to program evaluation to inform agencies and funders about effective practices and to to deliver best value outcomes for people these programs serve (Kemp, 2007, pp.23). In more recent years, mental health program evaluation has been implemented as a necessary tool to measure program efficacy through evaluation of client outcomes and satisfaction. Standard program evaluation practices utilize traditional subject-object research methods. Program evaluation methodology has been guided by traditional mental health theoretical models; these models are characterized by medical diagnosis, symptom management, therapeutic distance, pronounced power dynamics, and the prioritization of the clinical perspective over the perspectives of persons' served.

Informed by the Recovery Movement which first appeared in the 1990s, ServiceNet's mission has been evolving from a treatment and stabilization model to a person-centered recovery model. (Yarborough, 2015), but a new paradigm shift may be appropriate, given the new perspectives emerging.

While ServiceNet has embraced a theoretical shift that prioritizes empowering the voices of person's served, ServiceNet programs continue to be evaluated by the same top-down, traditional research methodology until this research project. The disconnect between the traditional DMH-inspired research model and the evolving person-centered theoretical orientation of ServiceNet has resulted in research endeavors that may not adequately illuminate whether ServiceNet is successfully meeting the *self-defined* needs of participants. These researchers utilized the principles of Participatory Action Research (PAR) through a multi-phase mixed methods project. These researchers utilized PAR to continually consult and center the voices of participants in the research process.

The conventional scientific evaluative tools have left gaps in the ability of researchers to adequately assess participants' self-defined needs and implement the vision of newer person-centered evaluation methods. These researchers explored whether the PAR model would be capable of bridging those gaps and addressing this issue. The hope was that the PAR model would more closely reflect ServiceNet's present-day evaluative values and mission that assert that social science evaluations are more complex than evaluations that are purely scientific in nature.

CHAPTER II

Historical Literature Review: The History of Mental Health Treatment Intervention Evaluation in America, A Review of the Literature

Introduction. Mental health treatment and research in the United States has historically been developed by experts with extensive training in mental health and social sciences and thus has been top-down, at times theory-driven, and often experienced by those who were intended to be helped as oppressive and not meeting their needs. Throughout American history, the care and treatment of what we refer to as mental illness has been driven by consensus theories about emotional and behavioral disorders.

This chapter reviews this history and how these theories continue to inform our contemporary research and treatment practices. The literature elucidates the oppressive effects (however unintended they may have been) that mental health treatment has had on individuals deemed to be mentally ill at each historical turn. Before institutionalization, “insanity” was criminalized or handled either by the family system or religious groups. During institutionalization, “mental illness” was medicalized and came under the purview of public health and the medical community. Since deinstitutionalization, mental health has been redefined, with many suggesting it is an aspect of social identity, and it has become more recovery oriented, person-centered, and community based.

The history of how mental health treatment has been *evaluated* and how research has been conducted during each era reflects the top-down, scientific and objectifying approach taken in the field until only recently. The political, religious, and popular culture dominant narratives during each era impacts the ways of thinking about mental health that treatment providers and researchers have today, ideologies which can often silence the voices of individuals who identify as having mental health problems. The purpose of this chapter is to provide a brief overview rather than a comprehensive history, in order to explain the context and rationale behind these researchers' theories and methods. Subsequent chapters will address the more recent shift towards addressing the lived experiences of individuals and their self-defined needs and own visions of recovery.

Before Institutionalization. Before institutionalization began (which occurred in the early 19th century), people with mental health problems in the United States were either cared for by family members, cared for by the church or a charity, or sent to jails or workhouses/ almshouses for the poor (Kemp, 2007, pp.1; NIH, 2015). "Insanity" was heavily stigmatized and generally believed to be caused by moral and logical ineptitude and/or religious or spiritual failing, as they were often thought to be "possessed by the devil" (Kemp, 2007, pp. 2). The Puritans in New England during this era promoted an individualistic, bootstrap philosophy (also known as the Protestant work ethic) in which salvation depended on one's morality and hard work, and this ideology still echoes throughout our culture and way of thinking about mental health today, particularly for individuals with mental health problems who are unable to work (Jimenez, 2015, pp. 95-99).

During the colonial era, ideas about the so-called "insane" and/or "idiots" were heavily influenced by religious beliefs (specifically Christianity), ancient Greek and Roman philosophy (such as humoral theory), the emerging western medical model, and the focus on mechanism by anatomists during the renaissance (NIH, 2015; Richet, 1910). For the most part, however, "insanity" was thought to be generally incurable and was essentially criminalized. "Treatment" (as we think of it today) was not given and rather, efforts were focused on controlling and/or containing “mad” individuals. No treatment evaluation or research was usefully conducted during this era.

However, just before and during the Revolutionary Era in the late 1700’s, attitudes about “madness” began to shift. So-called “insanity” started to become medicalized rather than criminalized. For example, physicians began to take an interest in, further categorize, and refine mental illnesses beyond older terms such as “psychosis”, “hysteria”, “mania”, and “melancholia” many of which had their roots in humoral theory and ancient Greek medicine (Bos, 2009). The following terms began to emerge in the field of medicine: “neurosis” introduced by William Cullen in 1769 (Cullen, 1816) as well as “manic depression” (known today as bipolar disorder) and “dementia praecox” (known today as “schizophrenia”), both introduced by Dr. Emil Kraeplin (Block, Green, & Holmes, 2014, pp.12). In England in 1796, William Tuke and other Quakers opened the York Retreat, which focused on moralism as treatment and sparked a trend toward treatment which was also catching on in the new nation, the United States of America (Charland, 2008, pp. xii, pp. 17).

In the very early 1800’s, Dr. Philippe Pinel and others led a “moral treatment” movement and mental health problems were beginning to be seen as potentially curable (Charland, 2008, pp. 17; Pinel, 1806). Pinel argued that if physicians unshackled the patients and treated them individually and with kindness, while categorizing different mental health problems and treating them in a tailored way, patients may be cured (Pinel, 1806, pp. 48-109; Kemp, 2007, pp. 3; Bloch, Green, & Holmes, 2014, pp. 319). Other early treatments that were popular during the 19th century included the “best rest cure”, particularly for hysteria and depression (Gilman, 1993) and phrenology. This theoretical shift toward treatment led to changes in public policy and the belief that mental illness is curable, but only if proper institutions are put in place. In the next section, the institutionalization of mental health treatment is described, kicking off with the moral treatment movement.

Institutionalization. Beginning at the turn of the 19th century, the moral treatment movement spread to provide better care and treatment for those deemed “insane”. Activists like Dorothea Dix began advocating for jailed “insane” people living in deplorable conditions (Kemp, 2007, pp. 3). Policy makers allocated resources to open mental hospitals, retreats, and asylums to treat the “mentally ill”. The first hospital open exclusively to people with mental illness opened in Williamsburg, Virginia in 1776 (Kemp, 2007).

Initially, only the wealthy had access to these institutions, such as the Pennsylvania Hospital founded by Benjamin Franklin and Dr. Thomas Bond in 1751 (University of Pennsylvania, 2015) and the Institute of Living in Hartford, Connecticut in 1822 (Institute of Living, 2016), though access to more and more of the general population opened up over time. In 1812, Benjamin Rush published “Medical Inquiries and Observations upon the Diseases of the Mind” and today he is known as the “Father of American Psychiatry”. His methods (as were the methods of many other doctors at the time) focused on blood letting, purging, and sensory deprivation as treatments for insanity (Rush, 1812) but he was also a social reformer and was for humane treatment as well (University of Pennsylvania, 2015). This effort contributed to the scientific theories about mental illness that have driven research and treatment for nearly two hundred years.

In 1844, the Association of Medical Superintendents of American Institutions for the Insane (AMSAII) was founded and later became the American Psychiatric Association (Grob, 1991). These events set the stage for psychiatry's dominance in the field of mental health treatment in America that still continues on today, though it now coexists along with other subfields, disciplines, and lines of mental health speciality such as psychology, social work, neuroscience, and more. The American Psychological Association was founded later in 1892 (American Psychological Association, 2016).

Between 1760-1820, industrialization (and the resulting geographic mobility it afforded) helped to spur the birth of the social work profession (Jimenez, 2015, pp. 51). The field of social work began during the Progressive Era, as women were able to increasingly access higher education and began to set up charity organization societies and settlement houses (Jimenez, 2015, pp. 54-70). Prior to these social work pioneers, the ideology of Social Darwinism, or the "belief that biological imperatives caused social problems such as inequality and poverty" (Jimenez, 2015, pp. 47), reigned and few intellectuals gave much thought to social and environmental causes for what are now often considered social problems. There was little data or research to support this view. The only known relevant statistical information being collected from the masses was from the 1840 census, which inquired about "idiocy/insanity" in only a single question (Douglas & Yeats, 1981).

Social Work emerged as a reform movement to better meet the needs of people being labeled "insane" before it became a profession. The major players in the creation of social work as a profession include activists such as Mother (Mary Harris) Jones, Mary Ellen Richmond, and Jane Addams (Jimenez, 2015, pp. 49-61). Mother Jones became involved in labor union reform and activism, particularly advocating for child workers and fighting to end child labor at the turn of the century (Jimenez, 2015, pp. 49-51). Mary Richmond was an early leader in the social work field and served 20 years as director of the Charity Organization Department of the Russell Sage Foundation, setting an example of strong case work and publishing a set of principles for doing social work (Jimenez, 2015, pp.56). Richmond was one of the first to emphasize "experiential and personal knowledge" in doing social work (Jimenez, 2015, pp. 56).

In 1889, Jane Addams and others established the Hull House (one of the first settlement houses), after the Toynbee Hall project in England which she hoped to replicate in America, and later became a labor rights activist (Jimenez, 2015, pp.60-61). In 1921, the American Association of Social Workers was founded, in part because Dr. Abraham Flexner and others called for "a more rational and systematic approach" to social work to give the profession authority (Jimenez, 2015, pp. 70). Social work activists and leaders like Mother Jones, Mary Ellen Richmond, Jane Addams, and others contributed to changing attitudes and beliefs about those who were labeled as "insane" by arguing that there are environmental and social reasons for human problems and that these individuals could be helped by alleviating their poverty and other environmental problems rather than focusing on potential biological or religious/moral factors. The social work profession promoted more collaborative, community-based approaches to helping people living with mental illness. Social work ethics and values has directly informed our work in this research project in challenging the dominant scientific, "objective" assumptions about research and treatment.

Locally, in Northampton, MA, Dr. Pliny Earle became the Northampton State Hospital's second superintendent in 1864 (Northampton State Hospital, 2016). Earle argued, much like Pinel before him, that insanity was curable (Earle, 1887) and he created a work therapy program whereby patients could work on a farm or in the greenhouse as part of their treatment

(Northampton State Hospital, 2016). The Northampton State School (as it was also known) was the only formal, public treatment facility available to those with mental health problems in Northampton until deinstitutionalization occurred and community-based organizations were established (such as the Hampshire Day House, which later merged with other organizations and became known as ServiceNet; ServiceNet, 2016).

Today, many continue to believe that mental illness can be treated successfully with many different therapies, medication, and increased social supports while others insist that these individuals should be warehoused and segregated from society due to their pessimistic view that mental illness is chronic and untreatable. Still, even while mental health issues were becoming increasingly medicalized and sufferers began to be known as "patients" and "invalids", very little evaluation of technique and scientific inquiry occurred surrounding new practices and a "doctor knows best" power dynamic was established, and in some places still prevails today.

Perhaps most credited this dynamic and approach is Sigmund Freud, who founded psychoanalysis and psychoanalytic theory during the 1890's and revolutionized how mental health was treated across the globe, as he was one of the first to place primacy on early childhood social relationships in the development of mental health problems, to discover the unconscious, to suggest a "talking cure", to differentiate between bereavement and depression (thusly, beginning a dialogue in the field about what is "typical" versus what is a clinical disorder), and many other accomplishments (Freud, 1917; Breuer, Freud, Strachey, & Freud, 2000; Berzoff, 2011; Mitchell & Black, 1995).

Around this time, mental health professionals were still attempting to categorize mental illness. The APA and the National Commission on Mental Hygiene (now known as Mental

Health America) created the *Statistical Manual for the Use of Institutions for the Insane* in 1917, containing 22 diagnoses (Statistical Manual for the Use of Institutions for the Insane, 1917), a precursor to the Diagnostic and Statistical Manual.

In 1914, the Harrison Narcotics Act was passed and criminalized possession of all narcotic drugs (Jimenez, 2015, pp. 12). During the 20's, prohibition of alcohol occurred and failed, at which point society began to focus on drug and alcohol use as a potential cause of mental health problems. Around the same time as these developments in America, Lev Vygotsky laid the groundwork for constructivism (which continues to impact how social science research is conducted today; Engel & Schutt, 2013) and systems theory was proposed by biologist Ludwig von Bertalanffy in the late 1920's though his idea was not utilized by family therapists and theorists until the 40's and 50's (Goldenberg & Goldenberg, 2013, pp. 90-91). These theories also contributed to a view of mental illness that was more social and relational, rather than biological or based on religious ideology.

The Eugenics movement, which was derived from Darwinian theory, sparked restrictive marriage and sterilization laws (Kemp, 2007, pp. 6; Jimenez, 2015, pp. 111-112, Darwin & Peckham, 2006). Between 1907 and 1940, 18,552 mentally ill people were sterilized while in the state hospital to prevent them from reproducing (Kemp, 2007, pp.6). The traumatic impact of this movement and the idea that mental health problems are purely biologically and genetically inherited rather than caused by environmental and social conditions still echoes throughout our culture today and the "nature-nurture debate" still impacts the modern discourse about mental health treatment.

In Europe during the 1920's, Melanie Klein was one of the founders of Object Relations theory, but it did not become ideologically influential in America until the 1980's (Mitchell & Black, 1995, pp. 86). Klein picked psychoanalytic theory up where Freud left off, though disagreeing with him on many points, and began a new school of thought which diverged significantly from Freudian ego psychology (which was developed by Anna Freud, Erik Erikson, and others). Klein's divergence is clear particularly in her development of the "paranoid-schizoid" and "depressive positions" over Freud's stage theory, emphasis on the importance of early "objects", and emphasis on "projective identification".

Perhaps one reason Klein's work is still so important in the context of this project is that she herself began as a patient under Sandor Ferenczi and had lived experience with severe depressions (Mitchell & Black , 1995, pp. 86), likely giving her "insider" insight over some doctor and scientist contemporaries who may have thought themselves to be relatively mentally "healthy". Thus, her work was one of the first movements away from purely intrapsychic or a "one person" psychology and towards an interpersonal or "two person" psychology. This literature review aims to highlight the historical work that led up to these researchers' choices for methodology, a methodology which rests on previous theoretical innovations such as Klein's.

During the 30's, Erikson went on to develop his stage theory of psychosocial identity (Erikson, 1968), placing a focus on identity which continues to inform mental health treatment professions. Erikson's contributions began a discourse about the importance of identity in mental health treatment. The current research project utilizes identity as having lived experience with mental health problems as an important factor for inclusion in these researchers' methodology.

During the Depression and World War II Era until the baby boom in the 1950's, asylums and mental hospitals began to expand and become overcrowded (Kemp, 2007, pp.9). A symbiotic relationship had developed between the psychiatrists and the asylums, with one legitimizing the other, without the perceived need for many checks and balances that treatments were actually effective or standardized (Grob, 1991, pp. 300). Popular treatments of the day included somatic treatments, fever therapy (Jules Wagner-Jauregg), diabetic insulin comas (Manfred Sakel), electroshock convulsive therapy (Ladislas Meduna, Ugo Cerletti), lobotomy (John Fulton, Egas Moniz, Walter Freedman) (Kemp, 2007, pp. 9; Bloch, Green, & Holmes, 2014, pp. 355-362), and hydrotherapy (Roback, 1961). During this era, an estimated 50,000 lobotomies were performed in the U.S. (Kemp, 2007, pp. 9). Overcrowding of state schools, hospitals, and asylums and reduced funding made living conditions less and less tolerable as 20th Century went on. This oppressive state of affairs occurred in conjunction with a lack of client voice in treatment and inadequate evaluation, serious problems that these researchers aim to rectify in this study.

During the 40's and 50's, the field of psychiatry underwent a serious reorganization and reform, spearheaded by Karl A. Menninger and others, in order to deal with some of the problems described above (Grob, 1991, pp. 24-43). There was a push for the mental health treatment field to become more scientific and accountable, perhaps because of the public's dismay over the deplorable conditions in the asylums and the treatments described above, which were beginning to be considered unethical (Bloch, Green, & Holmes, 2014, pp. 362). Also, war trauma cases resulting from World War II, large increases in the number of chronic long-term cases, overcrowding, inadequate facilities, and a lack of funding for therapeutic rather than custodial care all influenced the shift in thinking at this time as well (Grob, 1991, pp. 5-9). Mental health professionals often still cite lack of funding and inadequate facilities and/or staff ratios as major problems. Today, there is a high emphasis on privacy, human rights, and other ethical issues. These researchers consider ethics to be of paramount importance in the current study.

Between the 40’s and 60’s, Humanistic psychology developed from ideas put forth by Jean-Paul Sartre, Abraham Maslow, Carl Rogers, and others and a major emphasis was placed person-centered care, self-actualization, holism, creativity, existentialism, and positive psychology (Morris & Maisto, 1999; Kemp, 2007, pp.156), all of which are concepts still being taught and used today in all fields of mental health treatment. In the current study, the organization that these researchers are evaluating (ServiceNet) values “person-centered,” humanistic care so these researchers attempted to select an evaluation method that was also person-centered and as humanistic as possible.

The National Institute for Mental Health was established in 1949, a result of president Harry Truman signing the National Mental Health Act in 1946 (NIH, 2015), which reflected a strong political push towards research and accountability in the field during this era. Cybernetics was also developed at this time by mathematicians like Norbert Wiener, though these ideas would not be combined with systems theory and applied to the social sciences until Gregory Bateson did so in the 1970’s (Goldenberg & Goldenberg, 2013, pp. 20-21).

The field of psychology began to shift from being philosophical to rivaling the field of psychiatry in its influence on mental health treatment. By mid-century, behaviorism (which utilized stringent scientific methods in order to study only what is observable rather than speculative or interpretive; Skinner, 1953) and the development of attachment theory (which utilized scientific methods to provide support for and expound on previous psychoanalytic ideas such as Kleinian theory and theories by D.W. Winnicott and W.R.D. Fairbairn; Bowlby, 1969; Mitchell & Black, 1995, pp.112-138) became popular theoretical orientations.

The new view of psychology as a more legitimate science is important because this reflected society's mistrust of the doctor-knows-best attitude that became associated with psychoanalysis and psychiatry. In addition, the Diagnostic and Statistical Manual of Mental Disorders first appeared in 1952, which represented the first modern comprehensive attempt to use standardized descriptive categories for scientifically studied mental health problems by all mental health practitioners (American Psychiatric Association Mental Hospital Service, 1952; Crocq, 2015). The current DSM V is an influential factor in the current study, as these researchers qualitatively investigated participants' level of self-pathologizing, which may be influenced by the internalization of the descriptive labels used in the DSM.

Modern science-based psychopharmacology began in the 1940's with John Cade's development of lithium (Bloch, Green, & Holmes, 2014, pp. 8-10) Psychotropic antipsychotic medications such as Thorazine were developed and prescribed which later led to the discovery of antidepressants and other psychotropic drugs in use today. However, there are many critics of psychopharmacology, as there are many ethical issues to contend with, particularly with the child population, including issues of consent, health and safety, accountability, human subjects experimentation, among others (Bloch, Green, & Holmes, 2014, pp.167-168; Grob, 1991, pp. 146-156). Although there is still widespread acceptance of psychopharmacology in the mental health treatment field, some feel that certain medications (such as sedatives and some antipsychotics) constitute chemical restraints, the use of which is controversial. This is important to keep in mind, as this study asks participants about their medications and the organization these researchers evaluate provides medications and information about them to many of the participants in this study.

In 1955, The National Association of Social Workers was founded in part as an effort to establish social work as a professional field and establish standards of practice (NASW, 2016; Jimenez, 2015) Also in 1955, the Mental Health Study Act was passed by President Dwight D. Eisenhower, after which the Joint Commission on Mental Illness and Health was founded in order to create a nation-wide survey for improving methods and treatments (Kemp, 2007, pp.15; NIH, 2015). The JCMIH was incredibly influential on future program evaluation in the field, particularly because of the emphasis on prevention, improving conditions, human rights, training, and a return to more "moral" treatment methods (Grob, 1991, pp. 181-208). These events all reflect the societal push towards accountability in mental health fields.

The Great Society and the Civil Rights Movement during the 1960's resulted in gains and changes in Medicaid, Medicare, Social Security, and an increased emphasis on community treatment over institutional confinement (Jimenez, 2015). The Joint Commission on Mental Illness and Health's final report, Action for Mental Health, served to motivate professionals but failed to provide exact instructions for how to improve the systems of care in place at the time (Grob, 1991, pp. 209). Plans were being made to establish "community-based mental health facilities" and some states, such as California, were even delineating geographical regions called "catchment areas" within which to provide services (Grob, 1991, pp. 218).

During the 1960's, a cognitive revolution also took place in the field of psychology and much of the theories about computer science at the time was being applied to the human brain (Morris & Maisto, 1999). Aaron Beck developed Cognitive Therapy (and, later, Cognitive Behavioral Therapy; Beck, 1967). CBT is currently in widespread use as a treatment modality. Although these researchers utilize an arguably more psychodynamic intersubjective approach in the current study, cognitive theory is still heavily influential culturally speaking in regards to the ways of thinking about mental health and the deficit-focused dominant narrative.

The 1960's were a time of hope and change and many had idealistic notions that shifting from institutional to community care would solve most of the problems that field of mental health treatment faced. There was an antipsychiatry movement led by R.D. Laing and Thomas Szasz and the entire concept of mental illness was being called a farce and a form of social control (Kemp, 2007, pp. 15). Also, mental health professionals themselves began to feel that mental health problems were preventable and better treated through community care (Kemp, 2007, pp. 13; Grob, 1991). These shifts in attitudes led to the following major policy change:

> A new era in mental health care emerged in the 1960s when President John F. Kennedy signed the Community Mental Health Centers Act of 1963, which espoused treating people with mental illnesses locally rather than in large isolated state hospitals and led to the construction of federally funded community mental health centers across the nation, including several in Massachusetts. A community-based system of care has been evolving in Massachusetts since 1966 when the state Legislature enacted the Comprehensive Mental Health and Retardation Services Act. This measure decentralized the Department of Mental Health and established a robust network of services within each community so

that people could receive treatment, services and support close to their homes (Department of Mental Health, 2016).

Deinstitutionalization. The purpose of deinstitutionalization was to reintegrate people with mental health problems into the community and empower them to live meaningful lives in the community. Informed by new theories, such as cognitive and family theories, and a real optimism of the time that mental health problems could be ameliorated if individuals were no longer incarcerated and pathologized. The "doctor-knows-best" aspect of the dominant paradigm was finally chipping away, it seemed, and experiential, postmodern thought began to influence mental health treatment. The idealistic hope for deinstitutionalization was that the "mentally ill" would recover once they were treated in the community and when this did not occur, mental health professionals began to focus more on intersubjectivity and oppression as factors which were important to consider in treating mental health problems. The disillusionment that followed deinstitutionalization led to a further push away from top-down, objective views of mental health, which was not meeting the self-defined needs of those treated, towards an intersubjective, collaborative approach. Though many good things came from deinstitutionalization, the form (of treatment) simply changed while the substance (of not being able to meet the needs of those treated) remained the same.

As a result of changing legislation and attitudes, between 1950 and 1989, mental hospital populations dropped from 512,501 to 101,402 (Kemp, 2007, pp.19). Many professionals and legislators felt that deinstitutionalization was doing harm to former patients, as many became homeless, drug-addicted, and/or in jail because the community mental health organizations were not yet set up to provide enough assistance to them due to more funding being given to inpatient care facilities than outpatient (Kemp, 2007, pp.20).

Also during the 60’s, family theory and therapy had become well established by Salvador Minuchin (structural family therapy), Virginia Satir (experiential approach), and Murray Bowen (intergenerational therapy) among others (Goldenberg & Goldenberg, 2013). At that time, the hope was that once people with mental health problems were back in their communities, family therapy could be used to get at the complex, multi-person mental health issues which were difficult to treat while in the hospital. However, most individuals were not able to rejoin their families and the hopes professionals had for family therapy did not become realized at that time. However, more recent treatment research has focused on multi-person and systemic modalities, as will be described below.

Also during the 60’s, leaders of the multiracial feminist movement like Bell Hooks and Kimberlé Crenshaw were developing a new idea called “intersectionality” which claimed that different types of oppression were linked, such as gender oppression and racial oppression, and that one aspect of identity could not be understood without understanding the individual’s entire identity picture because each one affects social status and the subjective experience of oppression based on one identity factor may have an exponential effect when combined with another (Miller & Garrran, 2008). The idea of intersectionality is especially relevant to this research study when applied to disability identity and mental health stigma.

In 1964, President Lyndon B. Johnson declared “war on poverty” and in 1967, the Economic Opportunity Act was passed. Similarly, in 1971, President Richard Nixon declared “war on drugs”. Some speculated that the sudden recognition of these social problems occurred in part as a result of deinstitutionalization while others felt that homelessness (before deinstitutionalization and after) was caused by poverty (Kemp, 2007, pp. 63). Although "most anti-poverty programs were based on the culture of poverty model, which rested on the assumption that cultural factors were causes of poverty", the shift allowed for Community Action Programs to be set up to alleviate poverty in the community (Jimenez, 2015, pp. 77).

In 1977, President Jimmy Carter established the President's Commission on Mental Health in order to evaluate the nation's mental health system and in 1979, the National Alliance for the Mentally Ill was established (Kemp, 2007, pp.23). There was an increased focus on underserved groups such as children and the elderly and improving coordination of services (Kemp, 2007, pp.23). There was a push to evaluate how mental health treatment was faring since deinstitutionalization, as well as to fill in the cracks that previously hospitalized and incarcerated individuals may have been falling through in the new system.

During the 1970's and 80's, social identity theory, intersubjectivity, and self-psychology were developed. Social identity theory was developed (Tajfel & Turner, 1989) and would later have enormous effects on mental health treatment, particularly in explaining how in-group membership identity bias can lead to group conflict. In addition to this, Stolorow and others developed a new psychodynamic approach called "intersubjectivity" which involved the recognition that emotional experience always takes place within a field of relational exchange (Stolorow, Brandchaft, & Atwood, 1987), which flew in the face of scientific notions of objectivity that had reigned until then in the mental health treatment field. Also, Kohut developed his theory of self-psychology, which has been incredibly impactful in mental health treatment as well (Kohut, 1971). These developments reflected a trend away from striving toward objectivity and towards an acceptance of intersubjectivity, providing new lenses with which to view mental health treatment. This movement gave more voice to people receiving mental health treatment and put an emphasis on human rights and self-defined recovery.

During the 1980's, the work of Daniel Stern began to connect the dots between psychoanalytic ideas about child development and more research-based psychological ideas. He created his theory of the layered self and introduced the term "proto-narrative envelope" which described how pre-verbal experiences can be stored like a picture or story book for the child (Stern, 1985). Stern is only one example of interdisciplinary researchers who have attempted to unify the fragmented ideologies in the mental health field belonging to different schools of thought, such as psychoanalysis and research psychology. More work of this nature is needed, particularly around "self-report" methodology, which is currently valued in the social work field but devalued in psychology research. The current study utilizes self-report.

In 1981, President Ronald Reagan's Omnibus Budget Reconciliation Act cut federal funding for mental health treatment, putting states in charge of funding their own programs (Kemp, 2007, pp. 24; NIH, 2016). Some say that this was the beginning of a funding cuts trend in the field which has remained an issue (Kemp, 2007, pp. 26). In 1981, brain scanning techniques were developed based on the research of scientists like Dr. Louis Sokoloff (which led to PET scanning) and brain specialization discoveries were also being made (such as with Dr. Roger Sperry who discovered the specialised functions of the left and right hemispheres (NIH, 2016). So while federal funding was cut for treatment, important relevant scientific discoveries continued to be made at that time. This reflects the continued cultural dominance of more biological, objective, scientific inquiry over experiential, subjective inquiry.

Since the beginning of deinstitutionalization, mental health professionals have become more interested in ideas about mental health that other cultures have to offer, such as those stemming from Eastern medicine and religion. For example, many contemporary theorists and practitioners (such as with Dialectical Behavioral Therapy; Dawkins & Linehan, 1995) have borrowed Buddhist ideas (such as meditation, yoga, and mindfulness) and ideas borrowed from Chinese medicine (such as acupuncture) to incorporate into their treatments. This new interest in Eastern medicine is reflective of the shift away from the Western Medical Model which was top-down and objectifying. The organization these researchers are evaluating in this study utilizes mindfulness and other similar interventions frequently.

Also during the 80’s and 90’s, Family Therapy became more popular and widely used as well as studied by Larry Constantine and others (Goldenberg & Goldenberg, 2013). Also since the 80’s and 90’s, Bessel Van Der Kolk has been credited with revolutionizing how mental health professionals conceive of trauma as well as ushering in a new era focusing on childhood prevention of chronic trauma (van der Kolk, 2014). Because the current study evaluates programs which are heavily influenced by DBT, family theory, and trauma theory, these were relevant historical developments. Family therapy and trauma-informed therapy are becoming increasingly important in the field, particularly as a reflection of stepping away from one person psychologies, toward a view of mental health that encompasses more complexity. The implications of this shift on program evaluation are that researchers should include trauma-informed, multi-perspective, and systemic components to their studies, which these researchers have attempted to do in the current study.

In 1989, President George Bush declared that the 1990’s would be the “decade of the brain” and Neuroscience centers were being established (NIH, 2016). In 1990, only 20% of those with mental illness were receiving treatment but the amount being spent on treatment was extremely high (Kemp, 2007, pp. 24). In 1990, the Americans with Disabilities Act was passed to provide civil rights to those being discriminated against for having a physical or mental impairment (Jimenez, 2015, pp. 235). This policy offers legal protection to those with mental health problems and was considered an enormously positive shift by those working in the mental health fields, who assist those they work with in dealing with discrimination every day, including those working within the program being evaluated in the current study. Neuroscientists were discovering that not everyone had the same basic brain, as was taken for granted prior to that research, leading to newer ways of thinking of mental health including the neurodiversity movement and the push for legal protection for those who are differently abled.

In 1992, the Substance Abuse and Mental Health Services Administration was organized (Kemp, 2007, pp. 24). During the 1990’s to today, drug abuse remains a controversial topic, with a main theme of culturally destigmatizing it in order to provide better treatment, which proves difficult while drug use and possession remains criminalized. Dual disorder treatment became more common in the 1990’s (Kemp, 2007, pp. 38). Though mental health professionals attempt to provide “parallel treatment” for those with dual diagnoses (both mental health and substance abuse diagnoses), this care is rarely coordinated between those treating the mental health problems and those treating the substance abuse problems and outcomes remain poor (Kemp, 2007, pp. 38). This is significant to the current study because some of the programs which are being evaluated in this project are dual diagnosis programs.

Also in 1992, the APA and other institutions introduced and began to emphasize the importance of using “evidence-based practices” (or EBP’s) to achieve better outcomes, reflecting the continued push to make mental health treatment a more scientific endeavor to promote effective treatments and know “what works”. By 2004, states (such as California) were piloting federal policies (such as the Assertive Community Treatment model) around EBP’s (Kemp, 2007, pp. 78). As Joan Berzoff puts it while describing why many modern practitioners might reject Freudian ideas despite their continued relevance, “we live in a world in which mental health practices are being evaluated almost exclusively through the lens of quantifiable goals (i.e. the reduction of measurable symptoms, but not necessarily the improvement of the quality of a person’s life). We live in an era in which empirical validation trumps a more philosophical, imaginative, or interpretive way of understanding human behavior” (Berzoff, 2011, pp. 18).

During the 1980’s and 90’s, social workers focused on licensure enabling private practice and the NASW development of a code of ethics rather than social reform, a move which has been heavily criticised (Jimenez, 2015, pp. 79, 87). While conservative policies were being passed during the Clinton and Bush administrations, there was little outcry from the social work community, such as when a 60 year old welfare program was eliminated when the Work Opportunity Reconciliation Act of 1996 was passed (Jimenez, 2015, pp. 79). This move toward professionalization over reform is an example of the bias in the mental health field of “expertise” trumping practices that are more person-centered and informed by subjective experience, the latter of which is highly prioritized in the current study.

The Health Insurance Portability and Accountability Act (HIPAA) was signed by President Bill Clinton in 1996 (Civic Impulse, 2016). This law ensures privacy and confidentiality around personal health information for everyone seen by a medical or mental health professional. This law is reflective of the push towards protecting the rights of those with mental health problems and challenging the expert bias and professional privilege of those who provide treatment.

In 1999, the Surgeon General's report on mental health care in the U.S. found that only one third of those who have a diagnosable mental health condition (which is 20% of the population) receive treatment (Kemp, 2007, pp. 29). However, public awareness of stress, resilience, and coping skills improved during this era (Kemp, 2007, pp. 43). While only a fraction of those who could benefit from treatment received it, a more contemporary view on mental health treatment began to slowly seep into the cultural consciousness.

Also during the 90's, managed care, which was hoped would reduce healthcare costs and improve outcomes, became popular. Practices such as capitation, risk sharing, gatekeeping (which required primary care physicians to refer to specialists) became widely used (Kemp, 2007, pp. 55). The Mental Health Parity Act was signed by President Bill Clinton and passed in 1996 in an attempt to prevent insurance companies from putting a dollar cap on mental health treatments that was not comparable to other medical treatments (U.S. Department of Labor, 2008). These changes represent an attempt to deal with the major problems that had begun to spring up between insurance companies and providers, particularly after deinstitutionalization. In addition, the parity act was an example of policies being put in place specifically to reduce mental health stigma and discrimination. As mentioned previously, funding and discrimination are both thought to strongly impact mental health treatment outcomes as well as outcomes of treatment evaluation.

More recently, President Barack Obama signed the Affordable Care Act in 2010 to reform the entire health care system (including an expansion of Medicaid to people up to 133% of the federal poverty level; Jimenez, 2015, pp. 41) and the American Recovery and Reinvestment Act of 2009, an economic stimulus package in response to the recession which occurred in 2008 and increased funding for mental health and social welfare programs (Civic Impulse, 2016). Also, grassroots consumer-run services and programs are increasingly growing in popularity, such as the Recovery Learning Community, which will be discussed at greater length in the following chapter.

Throughout the history of mental health treatment in America (before, during and after institutionalization), religious, cultural, and political changes and events have dramatically impacted the attitudes and ways of thinking about mental health that have evolved into the modern attitudes and ways of thinking about mental health. Although the neurodiversity movement has been established during the current era, the older objectifying, top-down, and often oppressive ideologies and narratives of the past continue to inform mental health treatment in America. Although many mental health professionals from the past have rightly focused on humane treatment (such as the pioneers of the social work field who were mostly women facing discrimination in the face of the male-dominated fields of psychiatry and psychology), one could argue that ultimately treatment can only be as humane as it is self-aware, truly person-centered, non-oppressive, intersubjective, and inclusive.

Evaluation, Research, Ethics, and Modern Mental Health Treatment. The history of mental health research has been riddled with philosophical, ideological conundrums and ethical dilemmas. For example, in 1971, Stanford psychologist Philip Zimbardo’s famous prison experiment (Zimbardo, 1973) highlighted the ways that seemingly innocuous human subjects research can quickly spiral out of control and become oppressive and traumatizing, even when participants were not considered part of a "clinical" population. For these reasons and more, institutional review boards were developed at institutions of higher learning during the 1970's as a preventative measure and to ensure that the research being conducted would be ethical and safe. Deinstitutionalization began in that era and mental health treatment fields began to emphasize person-centered, non-oppressive treatment. Researchers began to ethically attempt to face their biases rather than attempt to be objective (which is now considered impossible by most treatment providers and researchers).

Today, the dominant treatment model in use is the recovery model. The notion that individuals with mental health problems could "recover" first began to appear in the 1990's (Yarborough, 2015). The NASW's definition of the recovery model, which appeared around 2004, as follows:

> A treatment concept wherein a service environment is designed such that consumers have primary control over decisions about their own care. This is in contrast to most traditional models of service delivery, in which consumers are instructed what to do, or simply have things done for them with minimal, if any, consultation for their opinions. The Recovery Model is based on the concepts of strengths and empowerment, saying that if individuals with mental illnesses have greater control and choice in their treatment, they will be able to take increased control and initiative in their lives. (NASW, 2006)

Informed by deinstitutionalization, the recovery model has come to replace the maintenance model before it. Though a necessary step in the evolution of mental health treatment, deinstitutionalization did not deliver on the expectations many professionals had for it. As previously mentioned, many individuals previously incarcerated in asylums were now homeless and their needs were going unmet (Grob, 1991, pp. 271, 301). Even individuals receiving the new community-based treatment did not have improvement rates as high as had been hoped for. The recovery model developed in part in response to these unmet needs as well as from the treatment model used for drug and addiction treatment (NASW, 2016) and it has been the predominant model in use since the President's New Freedom Commission on Mental Health, outlined in April, 2003 (Recommendations to improve mental health in America, 2004). The commission found that:

> Nearly all stakeholders describe a system in which access to desired services is very problematic, resulting in over reliance on crisis management rather than effective illness management. Stakeholders describe a wide range of systemic barriers including inadequate funding for services and supports; gaps in service and provider availability; absence of culturally competent services; lack of systemic orientation to recovery; inability to obtain insurance; lack of mental health insurance parity; low benefit limits; excessive management of mental health benefits; poor coordination among mental health service providers, supportive services, and schools; difficulty enrolling in indigent care programs; and high service cost. The challenges of living in the community with a mental illness are another important theme, including the problems of stigma, unemployment, inadequate housing, inadequate income supports, and far too frequent involvement with

> the criminal justice system. The comments of these 1,205 stakeholders clearly illustrate the very real challenges faced by America's mental health consumers and their families, and the service delivery system on which they rely... Consumers and family members also note that access to services is difficult when they have no way of knowing what is available, and many express an interest in more consumer-run services. (pp. ii, 5).

The recent research literature outlines many common areas for improvement in service programs, including staff training, more assertive outreach, improved psychoeducation (particularly around medications), and other issues. The following examples of program evaluations are typical for modern approaches used to evaluate mental health treatment today. Although far less oppressive than previous approaches, many problems still exist in the research being done. Namely, although researcher bias is better accounted for, not enough attention is paid to how the researchers identify in relation to mental health and not enough of the research is being done or informed by individuals with lived experience, an issue which will be addressed in subsequent chapters.

It appears as if even the most modern mental health treatment evaluation still uses researcher-led criteria by which to evaluate, rather than allowing the individuals receiving services to evaluate it themselves directly using their own methods, creating an "expert role" sort of bias in nearly all of the research. Embedded within that role, researchers often unwittingly perpetuate prior oppressive treatment and research due to unconscious assumptions about mental health informed by the dominant narratives (for example, untrue stereotypes that those with mental health diagnoses are more violent or lazy) discussed above that have evolved throughout history.

A modern example of how even more modern research is still informed by this top-down, researcher-led approach is the Mental Health Statistics Improvement Program survey put forth by Department of Mental Health, which ServiceNet modeled their survey after during its most recent program evaluation effort in 2012 (The Mental Health Statistics Improvement Program, 2004). The DMH questionnaire may have such a low response rate because it is not well informed by the experiences of people who identify as having mental health problems, as it is very long (57 questions) and time-consuming and uses academic terminology that may not be well understood by non-professionals (The Mental Health Statistics Improvement Program, 2004). The MHSIP was a government funded initiative by SAMHSA and their goal for research is "to improve the quality of mental health program and services delivery decision making at all levels of government through guidance and technical assistance on the design, structure, content, and use of mental health information systems" (The Mental Health Statistics Improvement Program, 2004).

Along with the survey, researchers also developed a toolkit describing how the survey was created as well as how to use it. The toolkit states that "Version 1 of the MHSIP Report Card set a precedent in its emphasis on being 'consumer-oriented'. That is, it was values-based in addressing specific concerns about how services benefit and affect consumers, and the choice of measures was influenced by extensive consumer input" (The Mental Health Statistics Improvement Program, 2004, pp. 9). However, the amount of consumer input is never described and the rest of the toolkit recommends what the *researcher(s)* should do in order to develop the project, rather than describing how a collaboration with consumers should be undertaken and/or how to center consumers in the decision-making process. Although the toolkit appropriately espouses the language, rhetoric, and ideology of person-centered evaluation, the final product does not appear to be a consumer-led research project.

What follows are examples of other modern evaluation research of mental health treatment.

Whitley, Gingerich, Lutz, & Mueser (2009) attempted to discover what factors promote or hinder successful implementation of community based mental health management and recovery. Over the process of two years, they performed qualitative interviews every 6 months with key informants and then used content analysis to look for cross-site barriers and facilitators of implementation of illness management and recovery. They found four themes: leadership, organizational culture, training, and staff and supervision. They are not very clear on what their "fidelity scale" really entailed, which was how they were measuring client outcomes. Also, they trained the staff in many different modules, so it is unclear if their project was an intervention, an evaluation of an intervention, or both.

Drake, Mercer-McFadden, Mueser, McHugo, & Bond (1998) conducted a meta analysis using 36 studies and studied outcomes for patients with dual diagnoses of Schizophrenia (and other mental health diagnoses) along with substance abuse, depending on whether their care was integrated (both diagnoses treated together) or treated separately. They found that integration improved engagement (i.e. therapeutic alliance?). They also found that certain "program features appear to be associated with effectiveness: assertive outreach, case management, and a longitudinal, stage-wise, motivational approach to substance abuse treatment." Some of the problems in the research were small samples, large drop-out rates, lack of control groups, not longitudinal enough, and over-use of self-report for measuring substance abuse. Few studies included medication intervention and compliance as variables, which may have been a confounding factor. Also, with such a heterogeneous population, other variables such as age, gender, trauma history, etc. should be included as well and type of substance(s) as well as severity of use should also be included.

Mueser, Corrigan, Hilton, Tanzman, Schaub, Gingerich, Essock, Tarrier, Morey, Vogel-Scibilia, & Herz (2002) contend that “Recovery occurs when people with mental illness discover, or rediscover, their strengths and abilities for pursuing personal goals and develop a sense of identity that allows them to grow beyond their mental illness”. Looking at 40 randomized controlled trials including people with mental illnesses, they found that psychoeducation, behavioral tailoring, relapse prevention, and coping skills training produced effective outcomes.

Howard, El-Mallakh, Rayens, & Clark (2003) also looked at client satisfaction using a person-centered approach. They found that clients were pleased with how much time they could spend with peers and staff and their comfort level when communicating with staff. They also found that clients would prefer to have more input in their treatment planning, more involvement of their families, and education about medications.

The above research outlines many issues which are relevant to program evaluation. However, it seems that these issues are often left out of the conversation in actual practice, particularly the subjective experience of the persons served. Many efforts to inquire about satisfaction of persons served use top-down approaches, putting the researchers in the role of the expert asking whatever questions they find relevant, regardless of whether or not this is truly relevant to the persons served. Future research should focus on the recipients of treatment having at least as much control and decision-making power over the evaluation project as the researchers, to reflect the collaborative nature of modern intersubjective theory. One problem is that studies being done by researchers who identify as having mental health problems themselves (roughly a body of literature sometimes referred to as “mad studies” or “neurodiverse research” are being excluded from academia and, thus, being suppressed by mainstream researchers who publish their work in peer reviewed, academic journals and are reported frequently in the media. This issue will be addressed more fully in the following chapters.

For example, the President's New Freedom Commission on Mental Health (Recommendations to improve mental health in America, 2004) solicited public comment from stakeholders in the mental health community, but the topics for which they solicited public comment were already outlined by the commission and were based on their own mission rather than topics based on what the mental health community itself may have chosen to focus on. The mere fact that such interchanges between policy makers and the mental health community members occur in such a skewed power dynamic is likely to be influencing the data collected and the conclusions which are reached, particularly if some persons served are not participating in the research due to the power dynamic. The commission also reports that treatment can often be “coercive”, such as with involuntary hospitalization, and that this significantly influences the effectiveness of the treatment given (pg. 20).

Overall, the mental health treatment evaluation field has yet to adequately reflect more modern ways of thinking about mental health and newer attitudes, such as those espoused by the neurodiversity movement (which will be addressed in subsequent chapters). Instead, mental health program evaluation is still mainly done using the older, dominant Western Medical model narrative which is top-down, researcher-led, quantitative, objectifying, and often experienced as oppressive by those who identify as having mental health problems.

CHAPTER III

Current Literature Review: Examining Current Perspectives of Mental Health and Mental Health Treatment Utilizing Narrative Accounts of Participant Satisfaction

Introduction. This thesis project entitled ServiceNet Participatory Action Research Program Evaluation, aimed to determine whether ServiceNet MHRS (Mental Health Research Subjects) is providing assistance that long term participants value on a personal level. The query was multi-faceted and accordingly this chapter is divided into sections which discuss concepts pertinent to the current MHRS model. The first section discusses the current conceptualization of people who struggle with their mental health and how they are viewed in mainstream society. Society's perception of participants with mental health challenges was important to this research project because service providers often deliver particular services based on this perception. This section would not be complete without an exploration of the dominant narrative of mental health and mental illness; This includes an analysis of a particular form of ableism called mentalism (Ingram, 2011). The first section also focuses on the implications of current institutional discrimination, and progress towards embracing neurodiversity.

The second section of this chapter examines the interconnectivity of the research team's work with the field of clinical social work. This section addresses program evaluation, anti-oppressive practice, and resource constraints in the context of funding restrictions. The second section evaluates the politics of resilience versus recovery and how this pertains to clinical social work.

The Conceptualization of Mental Health. ***The Dominant Narrative*.** Conceptualizing people who struggle with their mental health has been difficult throughout the course of history. Mental Health explanatory theory has evolved from viewing people with mental health challenges as criminals, to viewing them as having permanent brain diseases during the days of institutionalism to being viewed currently in less polarizing terms. (Please refer to chapter II for more detail on the history of mental health evaluative theory.)

The difficulty of conceptualizing mental health is currently compounded when considering mental health within the context of popular culture. Jeyn Roberts was quoted as saying, "There are three sides to every story. Yours. Mine. What really happened: the truth." This was closely correlated with David Epston's *Story, Knowledge, and Power* (1990). Epston discussed the implications of there being a dominant story, knowledge and power. Epston's theory stated that when a social group held power in society, the dominant group's story was heard, whereas when a social group did not hold power, their perspective was often ignored (p. 15). Epston pointed out that since no one could know objective reality, all knowledge required an act of interpretation. On an individual level, Epston felt that interpretations were based on personal life experiences and therefore created bias in all people. Lived experience was often much richer than what could be captured in one written story. For each instance in which one story was created, multiple offshoots of the main story were also present. However, if the other stories did not fit into the dominant framework they would be dismissed as irrelevant and not included in the primary narrative.

Epston looked at the basic analogies of story, knowledge and power and their implications in therapy and therapeutic relationships. If a person life's story did not fit into the dominant narrative they would be vulnerable to being misunderstood. Their opinions would have less sway and consequently their perceptions would be dismissed more easily. There would be less accountability if they are not treated with kindness, sensitivity or respect. Alternately, a person who was frequently misunderstood might internalize negative narratives about patterns in their life, and might not recognize alternate experiences that suggest a neutral or positive storyline.

The phenomena described in *Story, Knowledge and Power* was relevant to understanding the experiences and perspectives of the service providers and participants. Mental health service providers were part of society's dominant culture who partook in a narrative of self-sufficiency and autonomy; MHRS participants who were unable to live independently, did not share the dominant narrative.

Mentalism: A form of Ableism. In the context of this project, the interplay of stories, knowledge and power could be witnessed more clearly by understanding and dissecting the dynamics of mentalism. Kalinowski and Risser (2000) noted that mentalism was a form of ableist bias against people who had mental health diagnoses. Risser noted that mentalism was rarely acknowledged within the mental health field. Subsequently, a person who expressed dissatisfaction was often labeled as "treatment resistant" or dismissed as "not trying hard enough." Kalinowski and Risser (2000) delved into the limitations of the current biomedical model which stressed compliance with treatment. Mentalism inhibited recovery by undermining participants efforts towards self-determination, satisfaction and construction of meaning in their lives.

As clinical social workers, the concept of mentalism is relevant to this project because these researchers were creating a survey for people who were not part of the dominant narrative and were more vulnerable to mentalist bias. When studying marginalized populations, there were “ingroups” and “outgroups.” Risser talked about how mentalism was pervasive in language in a way that highlighted “us” versus “them.” In addition to the findings of Risser, neuroethics researchers, Andrew Fenton and Tim Krahn strove to reconceptualize the language surrounding people with mental health diagnoses “acknowledging that neurodiversity does not require a cure; changing the language from the current ‘condition, disease, disorder, or illness-based’ nomenclature.” (Fenton, Andrew & Khran, 2007). The implications of this research contributed toward the creation of a survey design that did not employ alienating language and impose “stereotype threat, ” or a situational predicament in which people are or feel themselves to be at risk of conforming to stereotypes about their social group (Shih, Margaret J.; Pittinsky, Todd L.; Ho, Geoffrey C.,2011).

Experiences of the Modern Mental Health Care System. Adame and Knudson (2007) researched and gathered narratives from clients who once considered themselves debilitated by mental health challenges. The researchers conducted a qualitative study and interviewed four participants for two and a half to three hours each. In this article, a “Recovery-Oriented therapeutic relationship” was defined as a relationship in which there was space for a person to explore how to find opportunities that aligned with their values and to contribute meaningfully to society.

Adame and Knudson’s article contributed to the pool of knowledge by gathering information from people who had shared similar mental health challenges to people who were using MHRS. A limitation of the Adame and Knudson study was the small sample size. When the participants in this study were encouraged to speak about their collective experience within the mental health system, they were able to find validation and connection among peers who could relate to their experiences. They found the act of becoming empowered to advocate for their needs greatly impacted their recovery processes. MHRS recipients had access to supportive and politically active peer groups, however, it was unclear how easily accessible these resources were. This relevant area of inquiry was further explored during the Recovery Learning Community and second ServiceNet focus groups.

In a study that focused on disempowering factors, Hooley (2006) studied expressed emotion (EE) or the measure of expressed negative bias of caregivers or family members towards clients with a mental health diagnosis. Hooley was able to show that subconscious mentalism had an effect on the prognosis of people who were struggling with their mental health. For example, a person suffering from First Episode Psychosis (FEP) who was being cared for in a setting where high EE was present had a lower chance of recovery. (Connell et al., 2014) This led to inquiry surrounding DMH survey methodology and whether they were able to understand the subtleties of mentalism and how this may have affected the survey assumptions and design.

In a study done by Cutcliffe (2015) of inpatient mental health care experiences in the United Kingdom, Portugal, Canada, Switzerland, Germany and Australia, people described their experiences as “personified by coercion, disinterest, inhumane practices, custodial and controlling practitioners and a gross overuse of pharmacological ‘treatments’.” This study looks at a cross section of people with symptomology that met the criteria for inpatient level of care. Some findings of this study were that participants felt dehumanized and exposed to treatments that did not align with their beliefs or values. Another plausible explanation was that the more pronounced the symptoms, the higher the burnout rate in clinicians, the less participants perceived that service providers were willing to form a therapeutic relationship with them. A limitation of this study was that it did not account for the perspectives of service providers in inpatient settings and towards participants. A question posed by the research team endeavored to examine if there was a correlation between higher levels of acuity and lower levels of service provider ability or willingness to form connections with participants.

This connected to Risser's assertion that if a participant expressed dissatisfaction they were often labeled "treatment resistant" or viewed as not invested in their recovery. If the expression of higher amounts of dissatisfaction were correlated to increased rates of mentalism, it would stand to reason that participants would not want to report if their needs were not getting met.

Chase et al. (2012) researched the compliance of long term participants and examined whether compliance and satisfaction rates were correlated. They found that when participants were compliant with treatment plans, often the tacit assumption by service providers was that they were satisfied with their care and their quality of life. However, the results of the research in this article indicated that although participants went along with treatment plans, they often were dissatisfied; they still felt varying levels of unhappiness and de-humanization.

There were many reasons for participants' dissatisfaction. The biggest complaint from program participants was feeling as though their voices were not being heard. Some other reasons for participant dissatisfaction included feeling as though they were receiving "conveyer belt services"(p. 577); services in which participants felt as though their providers were using treatment plan templates and not taking the time to do individualized work that accurately acknowledged specific goals of particular clients. Often participants did not feel that clinicians had enough time to gain a realistic understanding of what problems were troubling them. Participants appreciated clinicians who encouraged them to be involved in treatment planning (Chase et al., 2007).

Chase et al's study also provided insight into some of the experiences of participants who had received services on a long term basis. The study demonstrated that long term treatment led clinicians to be less goal directed in their work with participants. The findings that long term program participants were compliant although unhappy led our research team to question how an MHRS participant could advocate for themselves if they did not feel satisfied with their services.

In the context of the political change in mental health services in the 1990s that moved toward recovery-oriented treatment goals, 'recovery' was a new concept. The intention underlying this shift toward person-centered treatment was the advancement of mental health services. The treatment became 'recovery-oriented', however the term 'recovery-oriented' was loosely defined. There was no distinction between clinical recovery and personal recovery. Clinical recovery focused on the reduction of symptoms and the effectiveness of treatment is measured by how well the symptoms are reduced by the mental health system. Personal recovery was measured by the client and may not have included the reduction of symptoms or the use of the mental health system. In a 2015 study conducted on person-centered approaches to mental health and recovery, Yarborough et al. examined the definition of recovery.

Yarborough et al.'s team defined recovery from severe emotional distress in terms of degrees of functionality. The team conducted 177 semi-structured interviews with people diagnosed as Schizophrenic, Schizoaffective, Bipolar, or affective psychosis. They broke down recovery into three categories as follows: *getting by, getting back, and getting on* (Yarborough, et al., 2015). This distinction is important because it draws attention to the notion that 'recovery' is not a fixed concept.

Yarborough et al.'s study analyzed the definition of recovery in the context of mentalism and program evaluation. In this study, participants reported facing unique challenges requiring varying levels of mental health assistance. The levels of assistance were based on where participants perceived themselves to be in their trajectory towards recovery. Different individuals had varied levels of insight into emotional challenges, and varied goals for recovery. Consequently, the discussion section of Yarborough et al.'s study highlighted that for mental health services to be high quality, the services had to be able to be reflective of differing participant needs by being flexible and adaptive. Clinicians could be most helpful by naming recovery goals, measuring progress towards goals, and supporting needs consistent with varying stages of individual recovery.

Yarborough et al.'s longitudinal study also coded for themes that participants identified as important to their recovery. When participants talked about their recovery, they mentioned having a variable level of control over their symptoms and their lives. They also mentioned recouping losses as playing a role in their recovery. It was important for people to regain a sense of identity or discover a new identity. This included finding or rebuilding relationships, career and self-worth after a period of mental instability. Recouping losses also helped participants to be able to see themselves as people whose identities went beyond having mental health challenges. This aspect of the study showed our research team what had been helpful to some individuals in terms of becoming comfortable with their lives. These researchers wondered to what degree individuals using MHRS were able to find fulfillment. These researchers determined that it would be relevant to ask participants how they defined recovery and how they perceived their clinicians' ability to acknowledge their beliefs.

The Interconnectivity of this Research Project and Clinical Social Work. Our research project was connected to the field of social work through it's use and examination of program evaluation. This program evaluation project utilized Participatory Action Research (PAR) which worked to counterbalance the powers of societal oppression. These researchers analysed the utility of older subject-object research methods in comparison to the utility of PAR, Working toward partnership with the population was a new step in program evaluation. Refer to Chapter IV for more information about Participatory Action Research.

Thylstrup (2011) explored how to design a study that would accurately capture participants' perceptions of what influenced their motivation to stay engaged in modern treatment facilities. Eight different centers and 186 clients responded to this mixed method study. The Study had three goals:

1. Employing quantitative methods to examine correlations between client satisfaction with treatment, treatment retention, and outcome.
2. Locating narrative accounts about individual experiences of treatment.
3. Integrating the numerical and narrative data in order to enhance treatment providers' understanding of their participants' view of factors that contributed to their meaningful recovery.

The research conducted by Thylstrup laid a useful foundation for the research team to develop a program evaluation tool that would effectively increase our knowledge base about participants at ServiceNet. Using Thylstrup's study to bolster the research team's knowledge base about present day mental health treatment, these researchers were able to see the usefulness of having a mixed-methods study.

Wilson and Beresford (2000) examined the implication of the field of Clinical Social Work's stance as an anti-oppressive practice (AOP) on service users. This article analyzed the problems raised by the expert appropriation of service user's knowledge and the failure to acknowledge a social division for those giving and receiving care (p. 553). This research has led these researchers to challenge ways in which as clinical social workers, these researchers view our social identities and how these researchers may benefit from working within an ableist system. In the facilitation of RLC focus group, the participants expressed feeling experienced a social divide between peers and clinicians that often went unacknowledged. Using Participatory Action Research methodology, peers opinions about which questions would be important to ask participants took precedent. During the focus group, MSW candidate researchers took a passive role in assessing which questions would be most useful.

The Politics of Recovery. An article by Howell and Voronka (2012) explored the politics of resiliency and recovery movements. The article explores the history of the recovery movement. Initially, the term 'recovery' was coined by psychiatric survivors or people who had used the medical system and had found it to be disempowering and inhumane. During the days of institutionalized care, this group of activists found that there was little focus on the possibility of people recovering within the mental health system. Since then, ideas about resilience and recovery have been adopted by the medical model. "The terms have thus been re-figured: psychiatric experts now iterate that through recovery... those who are deemed to have disordered minds can live "meaningful lives" despite the ostensible permanence of their "illness." This understanding works to deny the possibility of a kind of recovery that would place patients or "clients" outside the remit of medical authority"(p. 2). Howell and Voronka's article pointed out that although modern psychiatry had adopted the term recovery, modern day systems often failed to analyze the political differences of "recovering from [mental health challenges using resiliency]" and "recovering in [the system]"(p. 4).

Introduction: The Politics of Resilience and Recovery in Mental Health Care (2012) showed that if these researchers looked at mental health from a social justice perspective, these researchers could find common themes: inclusion, recognition, politics, economics, equity and rights all played into the politics behind asking the simple question, "Are these services what you wanted and hoped for?" Resiliency placed more emphasis on the nature of the participant and less on the efficacy of the mental health system that supported them. With resiliency, the idea was that clients were able to bounce back from adversity. The discussion section of Howell and Voronka's article highlighted the possibility that creating and administering a survey had the potential to shift the focus from participant resiliency to focus more on service provider's efforts to creating an effective system. This study raised some questions about other ways in which clinicians may inadvertently benefit from mentalism.

Recovery and Resilience (2015) focused specifically on the perspectives of women of color who were experiencing varying degrees of emotional challenges. In the process of informing themselves more about what aided in recovery, the interviewers offered their personal contact information as well as information for support groups if the participants did not feel like contacting interviewers. They also provided access to completed reports of findings. *Recovery and Resilience* (2015) also pointed out that the act of doing research in and of itself influences the outcomes gathered. The subjectivity of the researcher affected the questions the researchers asked, the stories collected and their interpretations. *Recovery and Resilience (2015)* led the team to question how our backgrounds affected the survey tool.

The *Recovery and Resilience* (2015) report was helpful to read while taking into consideration the current political climate. The focus on recovery in the new mental health strategy promoted recovery as a measure of a person's overall quality of life. There was also a focus on personalized services and improving people's access to psychological therapies. This article highlighted that there was a dilution of focus on the needs of specific groups of people, especially in terms of race equality and an increase in compulsion within mental health services. The substantial changes in the way health, social care and welfare services were to be delivered, combined with the effect of spending cuts, were being felt more keenly by minority ethnic groups. This research shows how racism could enter into the mental health system. This led to the research team asking for participants to identify race in their responses. These researchers were curious as to whether people with target racial identities reported lower overall satisfaction than people with agent racial identities.

Anderson and Goolishian talked about the concept of 'Not Knowing' in their article *The Client is the Expert: a Not-Knowing Approach to Therapy* (p. 28). Anderson and Goolishian pointed out why it was important for clinicians to understand taking a stance of not knowing when in conversation with participants about their experiences. Similarly to Epson's article, Anderson and Goolishian's article submitted that 'reality' was arbitrary and dependent on people with power to define it. Furthermore, in order for an encounter to be therapeutic, a clinician needed to take care to not impose their definition of reality onto a person with whom they were working.

The article cited an example in which an individual had been struggling with schizophrenia for several years. This person talked about his experience of being asked conditional questions as a way to test whether his perceptions were based in reality. He felt that this was done as a way to assess his mental health. The person also felt that the act of testing his sense of reality had the effect of identifying him as inferior to the majority of people who did not share his sense of reality. Feeling as though service providers were trying to discredit his experience had inhibited this individual and his past service providers from forming therapeutic relationship. In his most recent therapeutic encounter, through a not knowing stance, he and his therapist had been able to explore the meaning of his perceptions and establish a trusting alliance. *The Client is the Expert: a Not-Knowing Approach to Therapy* demonstrated the role that not knowing played in creating trusting relationships. The article also showed how trust influences people's willingness to participate in creating shared meaning making experiences.

The concept of "Not knowing" guided this research design by reinforcing the importance of keeping an open mind. This principle also informed how our research team approached focus groups during this project. In our research, the team asked recovery counselors who had established trust with participants to distribute the surveys in hopes that more people would be interested in participating in this study (Anderson and Goolishian, n.d.).

Chapter Summary. In summary, this chapter of the literature review focuses on how experiences and perceptions of mental health can influence how effectively participants cope with different systems of care. The literature highlights some of the benefits and limitations of doing research and also how the experiences of researchers and participants can influence the ascription of meaning.

CHAPTER IV

Research Implications Literature Review: Re-centering Marginalized Voices in Mental Health Program Evaluation Through Participatory Action Research: Theoretical and Practical Implications

Introduction to Rationale for Chosen Research Methods. As discussed in Sections I and II of the literature review, clinical social work theory has evolved from problem-focused models towards more person-centered and strengths-based approaches. Despite the theoretical shift and overall momentum in the field towards person-centered care, program evaluation methods continue to reflect traditional standards of care that preference the voices of researchers, clinicians, and policymakers over the voices of person's served. The following section reviews emerging perspectives in the field of clinical social work and their implications for research practices, outlines ServiceNet's current service philosophy and practice model framework and program evaluation practices, and provides an introduction to Participatory Action Research as an emerging research model to foster greater congruence between person-centered theoretical frameworks and evaluation practices.

Emerging Perspectives: Mad Studies, Neurodiversity, and Postmodernism. *Mad Studies* is a movement of scholarship working to influence academia to include: "experiences, history, culture, political organizing, narratives, writings and most importantly, the people who identify as Mad; psychiatric survivors; consumers; service users; mentally ill; patients; neuro-diverse; inmates; disabled- to name a few…" (McWade et al, 2015). *Neurodiversity* is an emerging movement amidst the fields of education and psychology that seeks to shift away from problem-focused, symptom-reduction thinking into a more affirmative and gift-based ideology (Armstrong, 2013). The *Mad Studies* and *Neurodiversity* movements both aim to transform the legacy of a “othering” culture that further marginalizes individuals living on the psychological periphery, and views them as “objects for interpretation and research ‘on’ rather than ‘with’” (McWade et al, 2015).

Postmodern and client-centered theoretical models for psychotherapy call for deconstruction of existing explicit and implicit social narratives that influence definitions of “mental illness” (Anderson, 2001). While many social service agencies have yet to adopt the more radical ideologies of Mad Studies or Neurodiversity models, postmodern and person-centered approaches are becoming increasingly influential in government-funded mental health agencies (VandenBos, 1993; Rapp, 1998).

Hoffman (1990) reflects on her own experience with a postmodern approach, “the postmodern therapist comes… without any definition of pathology, without any idea about what dysfunctional structure to look for, and without any set idea about what should or should not change… I cannot believe that a therapist can go into a session with *no* ideas in mind, and I strongly feel that it is better to be aware of these ideas than not.” (11) Hoffman describes Postmodernist and person-centered therapies as an ongoing didactic process of “not knowing.” (Hoffman, 1990) “Person-centered” is thus not a place where an organization or clinician arrives, but rather an ongoing and dialectic re-examining of organizational agendas and biases. Thus, person-centered therapies exist on a multi-layered continuum and often continue to be influenced by psychotherapy’s authoritative legacy (Armstrong, 2013; McWade, 2015).

Emerging Theoretical Models and Current Evaluative Processes. *Mad Studies* and *Neurodiversity* theoretical models suggest that traditional subject-object research, even if in the name of “person-centered treatment,” is inherently limiting, particularly when the efficacy of programming is determined by goals as defined by service providers rather than by persons served (McWade, 2015; LeFrancois et al, 2013; Armstrong, 2013). As emphasized in postmodernism, the importance of critically analyzing the “lenses” of professionals to continually re-center the voices of clients, calls for a continually critically examined research process (Hoffman, 1990).

The incongruence of the traditional program evaluation methods with person-centered treatment models is representative of the ongoing domination of the professional mental health narrative over the persons’ served narratives (in spite of the emergence of person-centered language and treatment models.) The ideological shift in the field of mental health calls for new program evaluation models that re-center the voices of the persons served to determine whether or not services provided are helping them meet their own self-defined needs and goals.

ServiceNet: Person-Centered Services and Program Evaluation Practice.

ServiceNet’s Mental Health Recovery Services Division (MHRS) serves approximately 500 people in Hampshire and Franklin Counties through three contracted programs with the Massachusetts Department of Mental Health that all “embrace the principles of person-centered care” (ServiceNet, 2016). While the principles of person-centered care are embedded throughout the various services and programs offered, evaluation methods for how effectively “person-centered” these services are in early stages of development.

Larger program evaluation processes continue to utilize traditional subject-object research methods in which the researching body (DMH and the ServiceNet) defines the research questions and success measures. Research then evaluates how well services are supporting clients in meeting *the DMH and ServiceNet’s* goals on their behalf (Ganju, 2006). Funding structures in place often use person-centered words but retain traditional treatment aspects. For example, Federal and State grants often require reporting and evaluation methods to determine the efficacy of grant-funded services based on the success measures of the funders rather than the person's served. Thus, even in programs with person-centered foundations, the definitions of wellness, success, and recovery continue to come from the organization rather than the persons served.

This is a common incongruence between theory and practice among mental health service providers, and most current evaluation practices prioritize externally defined treatment objectives to evaluate program efficacy (McWade et al, 2015; Hoffman, 1990; Armstrong, 2013; Ganju, 2006). Due to a the independent nature of this research project, these researchers were unbound by allegiance to funding structures and had a unique opportunity to center the voices of person's served by ServiceNet and adopt a new paradigm of person-centered evaluation for ServiceNet's person-centered MHRS services.

Participatory Action Research (PAR). Participatory Action Research (PAR) asserts that "people in the organization or community under study 'participate actively with the professional researcher throughout the research process from the initial design to the final presentation of the results and discussion of their action implications" (Whyte, 1991; 1989). Participatory Action Research shifts the paradigm from traditional subject-object research that positions the researcher as "the expert" (Rogers & Palmer, 1994; King, 1998; McTaggart, 1991; Graves, 1991; Cousins & Whitmore, 1998). Israel et al (1998) outline the seven principles of PAR; "recognizes community as a unit of identity, builds on strengths and resources within the community, facilitates collaborative partnerships in all phases of the research, integrates knowledge and action for mutual benefit of all partners, promotes a co-learning and empowering process that attends to social inequalities, involves a cyclical and iterative process, and disseminates findings and knowledge gained to all partners." PAR can look quite different depending on the context of the research project; though these guiding principles distinguish PAR from other forms of research. By using value-based principles of collaboration, iterative processes, and transparency PAR significantly challenges traditional subject-object research methods in which researchers define the project objectives, parameters, and implementation.

Often PAR utilizes non-traditional research methods to ensure research subjects are able to communicate their perspectives freely, openly, and unbound by structures of academia (Rogers & Palmer, 1994). *PhotoVoice* projects are a frequent avenue for implementation of PAR research, and use non-traditional research methods to elicit participant voices through the visual medium of photography (Jurkowsky & Paul-Ward, 2007). PAR projects can take on many different forms, and project participants continually navigate the tension between innovation and credibility. Project participants often strive to utilize non-traditional research methods while maintaining credibility amongst academic circles to preserve possibility for systemic impacts of research (King, 1998; McTaggart, 1991; Graves, 1991; Jurkowsky & Paul-Ward, 2007).

According to Graves (1991) The National Institute on Disability and Rehabilitation, justified utilizing the principles of PAR research; "By involving the individuals who have the most to gain from the research effort, more relevant questions will be asked, more relevant and acceptable intervention strategies will be developed…" (Rogers & Palmer, 1994). PAR calls for greater discourse between stakeholders to collaboratively create shared research goals between consumers and providers (Rogers & Palmer, 1994).

Participatory Action Research (PAR) and Populations with Unique Needs. Participatory Action Research often utilizes focus groups to gather initial information to guide the project direction, receive feedback as the research progresses, and for consultation regarding interpretation of findings and next steps (Flores, 2007; Cahill, 2007; Cousins & Whitemore, 1998; Graves, 1991). In youth development work, PAR has proven as an effective method of generating innovative solutions to complex problems (Flores, 2007; Cahill, 2007). Youth development providers share similar systemic pressures and limitations as state-funded mental health providers; there is extraordinary pressure to conform to "evidence-based practices" that may or may not be most appropriate for the population served (Flores, 2007; Cahill, 2007).

Utilizing a PAR model requires that people with different power, status, influences, and facility with language come together-- an act which inherently challenges existing power dynamics (McTaggart, 1991; Rogers & Palmer, 1994). PAR serves as a theoretical model for reforming the traditional subject-object research approach and provides theoretical tenets to guide research, though inherently can be amorphous in its implementation. At the start of a research project, researchers must remain open to the constant evolution of the project as defined dialectically with research participants. PAR literature lacks specificity however, particularly for working with populations that may pose unique barriers for collaboration such as individuals often labeled as experiencing serious mental illness. Thus, program evaluation with populations with unique needs requires adherence to the principles of PAR, and researchers must problem-solve challenges directly with research participants and remain transparent about intentions and decision points.

Practical participatory evaluation's primary objective is to "support organization and program decision making and problem solving" while *transformative participatory action's* central objective is catalyzing some form of social change (Cousins & Whitmore, 1998). While a *practical participatory action* evaluation effort for Servicenet may result in organizational change, the primary objective is evaluative rather that catalytic.

CHAPTER V

Methodology

Introduction. These researchers developed a program evaluation survey for ServiceNet MHRS participants to understand how well services are meeting the participants' self-defined needs and goals. A central theme in mental health program evaluation literature is a discrepancy between participants' and service providers' ideas of what factors are relevant to client's overall well-being and successful utilization of different resources (Howell and Voronka, 2014). While mental health program evaluation literature is extensive and represents a wide range of different methodologies, these researchers found that most studies failed to evaluate whether the services are meeting the *self-defined* needs and goals of participants. Instead, and often inadvertently, most program evaluations evaluated success/improvement based on dominant narratives and definitions of mental health provided by clinicians/mental health workers, insurance providers, social policy measures, and broader cultural attitudes about mental health and well-being. For example, even more modern treatment evaluations cited in Chapter II, such Mueser et al (2002), focus on participant "coping skills" and other individualistic factors rather than evaluating systemic factors or definitions of mental health based on participant-led research. These researchers sought to re-centralize participant voices in all aspects of the program evaluation process.

Historically, ServiceNet program participants have been asked to complete annual DMH surveys developed by academics, policy-makers, and organizational stakeholders. ServiceNet's internally initiated satisfaction surveys have been staff-generated, inspired by the DMH surveys, and informed predominantly by professional social work theories and contract-driven objectives.

Thus, past ServiceNet satisfaction surveys have been more influenced by systems of care and provider's assumptions about mental health than the voices of the person's served. In the past, the response rates of ServiceNet's DMH inspired surveys has also been low. These researchers were interested in whether or not participant input would influence the survey response rate as well. These researchers were also interested in fully exploring participants' own definition of their needs, including discussion of potentially differing perception of satisfaction between program participants and staff, participant experience of boundaries of professionalism, and more generally the benefits and drawbacks of the current system of care. Through partnering with program participants, these researchers sought to generate a program evaluation tool to evaluate satisfaction based on opinions and values generated by participant voices, in a format that is respectful and accessible to complete.

These researchers utilized Participatory Action Research (PAR) to prioritize the voices of person's served in all aspects of project design and address the fundamental incongruence of many program evaluation efforts. PAR shifted the traditional subject-object roles by placing both these researchers and peers on a more equal playing field (Whyte, 1991; 1989). These researchers facilitated focus groups to collaborate with populations who both currently and historically utilized MHRS services. Using focus groups, these researchers conferred with peers within the ServiceNet system as well as peers of the Recovery Learning Community (RLC) who had been employed by and/or received support from ServiceNet in the past.

These researchers conducted three separate focus groups, two of which were with ServiceNet peer support workers and the third was with RLC peer support workers. The basis for this decision was informed by the literature review that indicated that the social identity of the interviewer has an influence the responses of the participants (Kalathil, 2011). The two ServiceNet focus groups were facilitated by two MSW student researchers and attended by peer counselors at ServiceNet. The first ServiceNet focus group was facilitated by Margot Reilly and Heather Crawford. The second ServiceNet focus group was facilitated by Margot Reilly and Caroline Evans. Four peer counselors attended the first ServiceNet focus group. In the second focus group there were also four peer counselors-- two who had attended the first group and two new members. The single RLC focus group was comprised of five people; one MSW researcher/peer counselor, Caroline Evans, and four peer counselors; The group was facilitated by one Caroline Evans and one peer counselor at an RLC center. In the RLC focus group, Caroline Evans, the facilitator acknowledged her identity as both as an MSW researcher and a peer counselor.

During the three separate hour and a half focus group sessions, these researchers first used a script to contextualize the purpose and objectives of the focus group. These researchers distributed written versions of the introductory script, as well as specific guiding questions for the discussion (see Appendix G). These researchers then facilitated discussion surrounding themes of survey objectives, formatting, accessibility, past challenges, and survey question development (see Appendix H). These researchers utilized the script of questions to re-center the discussion when participation quieted or stagnated, though participants primarily determined the flow of the group process.

During ServiceNet and RLC focus groups, facilitators were passively engaged in the content generation though they provided group process support through time keeping, occasionally synthesizing group consensus, posing clarifying/focusing questions when group discussion conflicted, and gently refocusing the discussion when conversation strayed to external matters. During ServiceNet and RLC focus groups, members were actively engaged in the process while facilitators adopted a passive role and did not contribute to discussion content. In the first ServiceNet focus group and the RLC focus group, facilitators remained more passive due to the idea-generation stage of the project and desire to allow the group process to unfold with minimal intervention. In the second focus-group, facilitators became slightly more engaged in facilitating and redirecting discussion towards the more specific objectives that involved refining and problem solving specific aspects of the survey.

Initial Focus Group Findings and Process. In the first ServiceNet focus group, there were six participants including two researchers and four peer support workers. The process was collaborative and constructive, with few disagreements about how to gather the data and what data to look for. These researchers began by reading a script which was intended to standardize the focus group process, state intentions/objectives, and create structure by identifying tentative goals. These researchers suggested coming up with "rules" for the group. Ultimately, the group then decided to create a "comfort agreement" instead. The comfort agreement included the following guidelines; privacy and confidentiality, openness/acceptance of ideas, respect others' opinions, using a non-judgmental attitude, not using phones during the group, and making an effort to stay on topic while speaking to the group. Three of four group members were actively engaged in the group discussion. One group member participated when directly asked for feedback by other group members, and this member always responded in agreement with the group consensus. The facilitators maintained a passive role in the content generation of the discussion, though they helped facilitate the group process by refocusing discussion on the focus group objectives and occasionally synthesizing group dialogue/consensus in response to a question. Facilitators always elicited feedback on any synthesized conclusions, and a peer counselor took notes on focus group discussion (see Appendix H). Facilitators did not take separate notes, and used the peer notes directly to generate the initial survey draft, which appears in the notes taken during the second focus ServiceNet focus group (see Appendix I).

The group decided that a single-page paper survey would be best to promote the best response rate. Focus group members felt that each question should have “yes,” “no,” and “unsure” check boxes followed by an explanation box. Group members unanimously agreed that there should be a blank page should participants want to elaborate further. The group identified areas of information that would be useful to know in order to improve services, including satisfaction about how well different types of needs are being met. These areas of inquiry around satisfaction pertained to overall needs (physical, safety, emotional, housing, personal growth, etc.), scheduling, medication and treatment information/options, staff support of participants’ self-defined goals, and feelings of empowerment in treatment process.

Focus group members also briefly discussed the wording and framing of the questions, though facilitators suggested that wording be refined in the second focus group. The group decided that an anonymous survey would be an ideal choice to encourage candid responses, and also hypothesized that providing incentives would improve the response rate. The group generated an idea to include a raffle ticket lottery incentive in the mailed survey, though group members were unable to determine how to facilitate these logistics in an anonymous, coherent, and fair way. An idea for an incentive included offering a chance to win a gift card, though group members agreed to think individually about the implementation of an incentive and revisit the idea in the second focus group discussion There was a debate mid-way through the meeting about boundaries, professionalism, and whether or not it would make sense for us to ask if participants' needs for physical affection are being met by staff. One participant shared a personal narrative about a time when a gesture of physical comfort was helpful to them. Facilitators validated this experience and affirmed the complexity of the issue. Based on a three to one vote, participants decided against including a question about needs for physical affection. The group decided that the next focus group would determine which questions would be included in the survey, which would be omitted, and how best to word and format questions.

In the RLC focus group, there were five total participants including four peer support workers and one MSW researcher, Caroline Evans, who had previous experience as peer support worker. The RLC focus group used the same script as the ServiceNet group with the only addendum being the exclusion of the "guideline" section (see Appendix G). The facilitators agreed that it felt unnecessary to presuppose the group would need to be guided by group rules. Similarly to the ServiceNet focus group, the facilitators took a passive role, and redirected the conversation if it became circumferential. The initial admission that the facilitator had shared experience of being a peer counselor may have contributed to creating an atmosphere in which participants were more forthcoming speaking about difficult aspects of their lived experiences within systems of care. The facilitators were responsible for keeping track of time as well. The notes for the RLC support group were taken by one of the peer support workers and then emailed to the MSW researcher (see Appendix A).

In the RLC Focus group, the participants felt that it would be helpful for ServiceNet to involve more peer support workers in the survey process. Participants placed high value on lived-experience with mental health challenges for providers within a system of care; they also placed value on experiencing the pros and cons of working service providers who they felt could not relate to their mental health challenges. The participants expressed concern regarding human rights, as one of the members of the group shared an account of a human rights violation occurring during their time employed at ServiceNet. The RLC peers discussed the importance of being able to provide peer support and connection to participants while they were taking the survey.

RLC focus group members felt that a program evaluation consisting of open-ended narrative interviews would be most beneficial. They expressed feeling that it was important for peers from a different agency to conduct the interviews in person with participants in order to ensure anonymity and reassure participants that this survey was being conducted for the purposes of increasing participants access to assistance outside of the agency, which the peers adamantly believed would improve participants quality of life. The RLC focus group members were unanimously concerned that participants would not feel empowered enough to voice their opinions concerning their hopes and dreams or need for change without guidance and support of those with similar life experiences.

Focus Group Ideological Divergence. These researchers came across notable differences between the responses of the RLC peer counselors and the ServiceNet peer counselors. The basis for holding the two different style focus groups was based on literature in which researchers found that the location of the interviewer influences the types of responses from participants and the perception of responses by the researcher (Anderson & Goolishian, n.d.; Kathalil, 2011). These researchers faced practical challenges around areas of significant ideological divergence between focus group conclusions (see Chapter VII: Discussion for further elaboration and implications for future research.) Due to project limitations, these researchers defaulted to the ServiceNet focus group conclusions due to their membership in the ServiceNet community. These researchers brought all RLC focus group results to the second ServiceNet focus group for contemplation and incorporation. Ultimately, the second ServiceNet focus group decided to uphold the original mixed-methods paper survey structure, though incorporated several of the RLC focus group's areas of inquiry including question wording and refinement and including two questions about human rights concerns.

As stated previously, the RLC focus group expressed feeling that it was important for peers from a different agency to conduct interviews in person with participants at ServiceNet in order to both ensure anonymity and reassure participants that this survey was being conducted in order to increase participants access to assistance outside of the agency. Ultimately, the in-person interview approach was out of the scope of this project, but had important implications for future research. Logistical limitations which impeded ability to use this approach include the fact that these researchers had to undergo a screening process and become deemed ServiceNet volunteers. The process that a third party peer agency would need to undergo to be cleared to meet with participants would have been time consuming and would have required more resources than were available to MSW student researchers. The peers would have needed to be instructed on how to administer the surveys free from bias. This was necessary as not to violate the ServiceNet peer counselors' and MHRS participants' confidentiality. NASW's Code of Ethics (2008) outlines "Social Workers' Ethical Responsibilities to Clients" and includes item *1.07 Privacy and Confidentiality* and identifies eighteen guiding principles to preserve client privacy. These researchers used the NASW Code of Ethics as the foundation of their conceptualization of this project, and prioritized client privacy throughout all phases of the research design and implementation.

Another research objective was to create a tool/method that could be easily utilized for regular program evaluation efforts. A qualitative approach would have been more difficult to implement with regularity. Also, the benefits of using a paper survey included a greater generalizability as well as more ease of distributing the surveys to a larger pool of participants with the use of a paper survey. However, the hope of the RLC peers to be involved as a third party agency is significant when considering implications for future collaboration.

Final ServiceNet Focus Group Process. During the second ServiceNet focus group, there were two researchers and four peer support workers. The two researchers read a short script which summarized the goals of the second focus group and included the draft of the survey tool with specific questions (see Appendix I). The two researchers practiced transparency about drafting process and brought forth several questions for collaborative problem solving. The two researchers and peer support workers collaborated on the wording of the questions, selected the most important content matter, clarified the survey length and the number of questions, and problem-solved formatting challenges.

Focus group members felt strongly that the survey remain on a single sheet of paper, though agreed that a double-sided survey was important to garner enough information. Focus group members felt that aesthetically, an extra sheet of paper for narrative responses was less appealing, but was worth attaching to create more spaces for participant elaboration and to yield qualitative data. Focus group members agreed that incentivizing survey responses through a raffle could be confusing and lead to disappointment, as well as potentially negatively affect confidentiality and/or privacy. Facilitators and focus group members agreed that providing an incentive *after* survey completion posed significant risk of compromising survey anonymity. These researchers posed the idea of enclosing a $2.00 cash incentive in every survey packet. One focus group member expressed skepticism that the $2.00 would serve as an incentive to complete the survey, and expressed that they would not personally feel more inclined to take the survey. While there was some disagreement initially among focus group members, members ultimately agreed that enclosing a $2.00 cash incentive would likely serve as an incentive, demonstrate gratitude and a spirit of collaboration, and preserve anonymity of survey participants.

Focus group members provided feedback on question coherence, and approved/denied/discussed proposed changes to question wording made by these researchers. The focus group discussion was based directly on the responses of the peer workers from the first ServiceNet focus group and the RLC focus group, and these researchers were transparent about places were focus group feedback was consolidated or modified. These researchers also mentioned the results of the RLC focus group including their hopes for a narrative/qualitative survey as well as suggestions for specific survey questions. Researchers were able to poll the second ServiceNet focus group for interest on further collaboration with the RLC in the future. Focus group members unanimously agreed that they were interested in ongoing involvement and dialogue around program evaluation efforts, and would like to be included in dialogue around collected data. These researchers intend to disseminate and discuss research findings with both Smith College School for Social Work community and the ServiceNet community.

Sample. Anonymous mixed-methods surveys were sent out to a random sample of 102 recipients of MHRS CBFS services in Hampshire County, MA. To participate in the study, individuals needed to be currently be enrolled in ServiceNet's Hampshire County MHRS program. There were no exclusions from this group. All Hampshire MHRS participants regardless of age, race, ethnicity, socioeconomic status, gender identity, or sexual identity were eligible. These researchers acknowledged many differences across this population of people in terms of degree of recovery, symptomology, needs for services, perception of ableism, and diagnoses. The demographic information these researchers have about our sample versus the population indicates that our sample was a fairly representative sample of the population (see Table 1 below for sample and population demographics).

An initial random sample of 90 participants was selected by ServiceNet's Utilization Management Coordinator using ServiceNet's MHRS client database, from that sample, 60 of those names were selected at random to pilot the survey. ServiceNet's Utilization Management Coordinator screened the list for names that were inactive due to institutional placement (usually hospitalization or incarceration). Additional names were selected at random to fill out the groups of 60 and 30. After two weeks of initial survey distribution, the remaining 30 participants were surveyed in a second round. 12 surveys were refused and returned unopened. In attempt to reach target response rate of 45 participants, 12 more names were then selected at random from the MHRS client data base using the same screening method, and surveys were distributed for the third and final round. These researchers received 34 responses.

Under Seth Dunn LICSW's direct supervision at ServiceNet, undergraduate interns from the Smith College Psychology Department assembled survey packets that included a letter of explanation (see Appendix E), two dollars incentive, survey tool (Appendix F), and a postage paid envelope addressed to Seth Dunn LICSW (with no return address.) Sealed survey packets with the names of randomly selected survey participants written on the outside were distributed to participants by their Recovery Counselors. Recovery Counselors were provided with a short script to contextualize the survey and explain procedures for returning the survey (see Appendix D). Peer focus group members felt strongly that distribution in-person by "someone trusted" by participants would evoke a greater response rate and more honest responses.

This survey distribution method ensured complete anonymity and confidentiality and returned surveys contained no identifying information, thus no consent forms were needed. The program evaluation was conducted in a double-blind format; ServiceNet recovery counselors distributed surveys and undergraduate interns entered the data in Survey Monkey. These researchers only had access to aggregate and de-identified data for their data analysis, and did not have direct contact with survey participants.

For the demographic data gathered on the survey tool, these researchers and focus group members decided together that gender, team, and age range were the most important variables to be able to compare. These researchers felt that it was imperative to include race, though focus group members felt ambivalent about inclusion of this category. These researchers decided to include the category regardless to honor Smith's anti-racism thesis objectives. These researchers were also curious as to whether participants of different races experienced differences in the quality of care they received. While important to run regression analyses to compare satisfaction across different identify variables, the central research question regarded overall ServiceNet client satisfaction. These researchers navigated the tension of preserving survey anonymity while also gathering demographic information to compare satisfaction across different identity variables. These researchers decided to provide fill-in-the-blank responses for race, gender, and team membership to avoid forcing participants to place themselves in predetermined categories and practice respect for individual self-identity, please see Discussion for further elaboration on the benefits and drawbacks of this approach.

Data Analysis. Our collection approach was anonymous and mixed methods. Quantitative data was taken in the form of *yes, no* or *unsure* queries with a narrative box labeled *Please Explain* (see Appendix F). Under the supervision of Seth Dunn LICSW, undergraduate interns entered paper survey data into Survey Monkey. These researchers only had access to aggregate and de-identified data for data analysis. Descriptive statistics on quantitative responses were derived and securely stored using Survey Monkey software based on data entered by Smith College undergraduate interns. Comparative statistics on quantitative results were completed by these researchers using SPSS software. These researchers created fill-in-the-blank responses sections for team, race, and gender on the survey. This decision was made collaboratively with the focus groups to provide additional freedom for individual participant's self-categorization. In order to run statistical analyses, these researchers subsequently grouped participant responses into categories. For the gender category, these researchers grouped responses into the following four categories: 1= Female, 2= Non-Binary, 3= Male, 4= Unknown. For the race categories, these researchers grouped responses into Race- 1= Person of color, 2= Multi-racial, 3= White, 4= Unknown or No Response. For Age, in order to preserve anonymity, participants were asked to check a box indicating their age range. These researchers coded 1= 21-29, 2= 30-45, 3= 46-60, and 4= 61 and older.

These researchers collaboratively analyzed qualitative responses. Of 34 total respondents, 27 contributed narratively. These researchers used a random number generator (Random.org, 2016) to select 7 participants who contributed narratively (25%) to determine interrater reliability and ensure that there was at least 80% agreement for each variable (McHugh, 2012). These researchers then divided up the remaining participants into three subgroups and each researcher coded their individual participant subgroup for the following categories: trust in others, hopefulness, connection, narrative coherence, congruence between yes/no response and narrative response, self-compassion, self-pathologizing, self-trust, and locus of control. These researchers coded the following variables as 1=low, 2=medium, 3= high; hope, emotionality, narrative coherence, connection, self-compassion, self pathologizing, and self trust. Several variables were initially coded using different scales. Trust of others was coded as 1= mistrust, 2= neutral/unknown, and 3=trust. Identity factors were coded as 1= not mentioned, 2= mentioned once, 3= mentioned more than once. Locus of control was initially coded as 1=internal, 2=mixed, 3=external.

After coming back together and comparing coding results, each variable was discussed at length by the coders in order to clarify how they were to be operationalized. (For example, if the participant had two sentences or less, they were to be coded as “unknown” rather than as high or low on a particular variable). These researchers initially were going to code for identity factors mentioned in the narratives. No participants mentioned identity factors, so this category was dropped from coding and analyses and these researchers decided to run regression analyses on demographic information. These researchers unable to code for emotionality because it was too subjective, general, and difficult to define based on the fact that these researchers would not able to assess the tone or meaning based on the method (i.e. paper survey). These researchers collaborated on definitions of each variable via discussion, except where otherwise specified (such as when a dictionary was used). These researchers used Cohen's Kappa to ensure interrater reliability. For all of the qualitative variables, κ= 1.0 because these researchers reached 100% agreement for each variable post discussion, majority consensus, and re-coding (McHugh, 2012). Final variables and operationalized coding definitions follow.

Trust in others was defined as belief that ServiceNet providers are "reliable, good, honest, effective, etc." (Trust, 2015). For the "trust in others" variable, these researchers initially agreed on 5 out of the 7 participant answers. These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion. The final coding categories were operationalized as follows: 1= mistrust, 2= signs of both, 3= trust, and 4= unknown.

Hopefulness was defined as the feeling that what is wanted can be had or that events will turn out for the best (Hope, 2016). For the hopefulness variable, these researchers initially agreed on 3 out of the 7 participant answers. These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion. After discussion, the final coding categories were operationalized as follows: 1= hopeless, 2= mixed, 3= hopeful, 4= not enough information.

Connection was defined as feeling akin to, therapeutically allied with, bonded to, and united with their ServiceNet providers. For the connection variable, these researchers initially agreed on 3 out of the 7 participant answers. These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion. After discussion, the final connection coding categories were operationalized as follows: 1= disconnected, 2= mixed, 3= connected, 4= not enough information.

Narrative coherence was defined as when a participant's narrative had a clear, non-tangential beginning, middle, and end using the informal rules and standards of the English language, notwithstanding small punctuation or spelling errors, to the extent that the reader is able to comprehend their general message. The coding categories included the following: 1= low, 2= medium, 3= high. For the narrative coherence variable, these researchers initially agreed on 2 out of the 7 participant answers. These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion.

Congruence between the quantitative and the qualitative responses was defined as when the participant's yes/ no/ unsure response seemed to match the tone of what they wrote in their narrative. For the congruence variable, these researchers initially agreed on 77.32% of participant responses (126 possible responses total, for 7 participants and 18 questions). These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion.

Self-compassion was initially operationalized as when a participant's narrative indicated they feel a sense of kindness towards themselves or not. After these researchers only agreed on 2 out of the 7 participant responses, these researchers re-operationalized self-compassion as when a participant's narrative indicated that they feel a sense of kindness towards themselves as opposed to condemning or judging the self. The coding categories included the following: 1=

self-judgment/self-condemning, 2= neutral, 3= self-compassionate. These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion.

Self-pathologizing was defined as as when a participant's narrative indicated that they view or characterize themselves as medically or psychologically abnormal, inferior, or problematic. These researchers attempted to determine based on what was written the degree to which the participant internalized the diagnostic labels being given them. These researchers operationalized it initially by using the following coding categories: 1= low in self-pathologizing, 2= moderate or mixed in self-pathologizing, 3= high in self-pathologizing. After only agreeing on 2 out of 7 participant responses, these researchers re-operationalized the variable by using the following coding categories: 1= self-normalizing, 2= neutral, 3= self-pathologizing. These researchers utilized discussion, re-conceptualization of the variable, and majority consensus in order to settle disagreements and achieved 100% agreement post-discussion.

Self-trust was defined as when a participant's narrative indicated that they themselves are "reliable, good, honest, effective, etc." (Trust, 2015). The coding categories are as follows: 1= low self-trust, 2= medium self-trust, 3= high in self-trust. Initially, these researchers agreed on 3 of the 7 participant responses, but utilized discussion, re-conceptualization of the variable, and majority consensus in order to achieve 100% agreement.

Locus of control was defined as when when a participant's narrative indicated that either they or others are the driving force in their own recovery and either they or others have more control over their lives. The coding categories used are as follows: 1= internal locus of control, 2= mixed, 3= external locus of control. These researchers initially did not agree on any of the 7 participant responses, but utilized discussion, re-conceptualization of the variable, and majority consensus in order to achieve 100% agreement.

CHAPTER VI

Findings

Introduction. This study used a mixed-methods survey design for the purpose of evaluating ServiceNet program participants' level of satisfaction with ServiceNet MHRS services. The survey tool sought to explore if program participants feel ServiceNet Services are supporting them to meet their own self-defined needs and goals. In the following chapter, results of the data analysis are presented and discussed including a demographic analysis of the sample, descriptive statistics gathered by quantitative responses, and comprehensive qualitative analysis will be discussed.

Sample Demographics. MHRS Recovery Counselors delivered 102 surveys to ServiceNet MHRS program participants. Twelve surveys were refused and returned by Recovery Counselors to Seth Dunn LICSW, ServiceNet's Director of Quality Management. Fifty six program participants received the survey envelopes and did not return them. Thirty four surveys were returned completed (n=34). Of the 34 survey participants, 41.2% identified as Male, 52.9% identified as Female, 2.9% identified as Non-Binary, and 2.9% did not identify their gender (marked as unknown). The racial breakdown of survey respondents included 8.8% People of Color identified, 2.9% Multi-racial identified, 70.6% White identified, and 17.6% Unknown or No Response. To preserve anonymity, respondents were asked to check a box with their age range and 0% identified between 21-29, 47.1% identified between 30-45, 35.3% identified between 46-60, 14.7% identified as 61 and older, and 2.9% of respondents were of unknown age. The mode age range was 30-45 with nine respondents.

Table 1: Descriptive Statistics of Demographic Data (N=34)

Demographic	**Frequency**	**Percentage**	**Percentage in entire MHRS Population**
Gender			
Female	18	52.9%	51.9%
Male	14	41.2%	48.1%
Non-Binary	1	2.9%	0%
Unknown	1	2.9%	0%
Race			
White	24	70.6%	64%
Person of Color	3	8.8%	6.5%
Multi-Racial	1	2.9%	1.4%
Unknown	6	17.6%	28%
Age Range			
21-29	0	0%	7.5%
30-45	16	47.1%	35%
46-60	12	35.3%	39.7%
61 and older	5	14.7%	17.8%
Unknown	1	2.9%	0%
Team			
Northampton MHRS Team 1	9	26.5%	25.2%
Northampton MHRS Team 2	7	20.6%	23.8%
Amherst MHRS Team 3	9	26.5%	28.5%
Northampton MHRS Team 4	2	5.9%	16.8%
East Street House MHRS Team 5	0	0%	2.8%
Hatfield Farm MHRS Team 6	1	2.9%	2.8%
Unknown	6	17.6%	0%

Descriptive Statistics and Quantitative Findings. Question five on the survey tool queried participants to identify what needs ServiceNet was supporting them to meet. Participants were instructed to *check all that apply* for the following focus-group identified needs: emotional support, housing, voice in your treatment, medication information, personal growth, recreation/fun, spirituality/religion, physical safety, emotional safety, transportation, wellness, legal support, personal empowerment, independence, social connection, community resources, educational, finances, employment, none of the above. The four needs that participants marked as met with the most frequency were housing (67.65%), personal growth (61.76%), emotional support (58.82%), and transportation (55.88%). The four needs that were identified as met with the least frequency were legal support (14.71%), educational (14.71%), employment (11.76%), and spirituality (8.82%.) One participant (2.94%) marked that "none of the above" were met for them in relation to needs.

Table 2: *Descriptive Statistics of Needs Met by ServiceNet (N=34)*

Need	**Frequency**	**Percentage**
Housing	23	67.65%
Personal Growth	21	61.76%
Emotional Support	20	58.82%
Transportation	19	55.88%
Independence	18	52.94%
Voice In Your Treatment	16	47.06%
Medication Information	16	47.06%
Emotional Safety	16	47.06%
Recreation/Fun	15	44.12%
Social Connection	15	44.12%
Community Resources	13	38.24%
Personal Empowerment	11	32.35%
Wellness	11	32.35%
Finances	10	29.41%
Physical Safety	9	26.47%
Legal Support	5	14.71%
Educational	5	14.71%
Employment	4	11.76%
Spirituality	3	8.82%
None of the above	1	2.94%

Questions 6-18 received response rates between 29 and 33 participants. The following table demonstrates data results of questions 6-9, 11-12, and 14-18 (question 10 and 13 utilized a different format and results follow in Table 4 and Table 5):

Table 3: Quantitative Results for Questions 6, 7, 8, 9, 11, 12, 14, 15, 16, 17, 18 (N=34)

Question	**Response #**	**Yes (%)**	**No(%)**	**Unsure (%)**
6. Do you feel your Individual Action Plan (IAP) meets your vision of recovery?	33	75.76%	12.12%	12.12%
7. Does staff support your self-defined idea of recovery?	33	78.79%	12.12%	9.09%
8. Do you feel ServiceNet staff consistently pay attention to your needs?	31	77.42%	12.90%	9.68%
9. Do you feel you have enough information about your medications from your providers?	31	80.65%	12.90%	6.45%
11. Do you feel you are treated like a human being?	31	90.32%	3.23%	6.45%
12. Do you feel that ServiceNet staff are available when you need to talk to them?	30	76.67%	13.33%	10.00%
14. Do you feel that your opinions are respected by ServiceNet staff?	32	75.00%	12.50%	12.50%
15. Do you feel like you will be heard if you report that you are unsatisfied with your services?	32	65.63%	15.63%	18.73%
16. Do you feel informed about how to make a human rights complaint?	29	62.07%	13.79%	24.14%
17. Do you feel that staff care about you?	31	80.65%	3.23%	16.13%
18. Do you feel that staff are well-trained enough to meet your service needs?	30	80.00%	13.33%	6.67%

The most affirmative responses from participants included 90.32% feel that they are treated like a human being, 80.65% of feel that they have enough information about their medications from their providers, 80.65% of participants feel that staff care about them, and 80.00% of participants feel that staff are well-trained enough to meet their service needs. While 80.65% of participants feel that staff care about them and only 3.23% feel staff do not care about them, question 17 also yielded high levels of uncertainty; 16.13% of participants expressed that they are unsure if staff care about them. The two questions with the lowest rates of positive response included questions 15 and 16; only 65.63% of participants feel that they will be heard if they are unsatisfied with their services and 62.07% of participants feel informed about how to make a human rights complaint. Both questions 15 and 16 also yielded the highest levels of uncertainty-- 24.14% of participants feel unsure if they feel informed about how to make a human rights complaint and 18.75% of participants are unsure if they feel that they will be heard if they report they are unsatisfied with their services.

In Tables 4 and 5, responses to questions 10 and 13 are delineated. Table 4 demonstrates the responses to the questions as stated in the survey. Table 5 adjusts the results by excluding participants who selected “not applicable to me” on the survey tool.

Table 4: Descriptive Statistics for Questions 10 and 13 (N=34)

Question	**Response #**	**Yes (%)**	**No(%)**	**Unsure (%)**	**Not Applicable to Me (%)**
10. If you received medication from a nurse who comes to where you live, please respond to this question. Does the nursing schedule work well with your daily routine?	31	48.39%	16.13%	0.00%	35.48%
13. Have you been given the option to discuss a plan to graduate from the program if you want to?	32	34.38%	31.25%	15.63%	18.75%

*Table 5 Quantitative Results for Questions 10 and 13 Adjusted to Exclude Not Applicable Participants_*

Question	**Applicable Responses (n)**	**Yes (%)**	**No(%)**	**Unsure (%)**
10. If you received medication from a nurse who comes to where you live, please respond to this question. Does the nursing schedule work well with your daily routine?	20	75.00%	25.00%	0.00%
13. Have you been given the option to discuss a plan to graduate from the program if you want to?	28	42.31%	38.46%	19.23%

Question 10 and Question 13 yielded the highest levels of dissatisfaction. As demonstrated by Table 5, for Question 10, 75% of participants who receive medications from a nurse where they live feel the nursing schedule works well with their daily routine while 25% feel that the schedule does not work well with their daily routine. For question 13, only 42.31% of participants who want to graduate feel that they have been given the option to discuss a plan, while 38.46% of participants who want to graduate feel that they have not been given the option to discuss a plan and 19.23% are unsure if they've been given the option to discuss a plan.

Qualitative Analysis. Participants who contributed narratively were coded for trust in ServiceNet providers, hope, connection (to ServiceNet and ServiceNet Providers), narrative coherence, self-compassion, self-pathologizing, self-trust, and locus of control. For comprehensive definitions of these concepts, please see Chapter V: Methods. Participants contributed varying amounts of narrative; depending on the variable, these researchers were unable to code for qualitative analysis between 25.53%% and 66.59% of participants. The following section contains a set of two tables for each variable; the first delineates the entire sample (n=34), and the second is adjusted to remove the participants who did not contribute adequate narrative relevant to the coded variable.

Table 6: Descriptive Statistics for Trust in Providers (n=34)

Coded Variable	**Mistrust (%)**	**Signs of Both (%)**	**Trust (%)**	**Not enough information (%)**
Trust in Providers	14.71%	20.59 %	38.24%	26.47%

Table 7: Descriptive Statistics for Trust in Providers (Participants With Adequate Narrative) (n=25)

Coded Variable	Mistrust (%)	Signs of Both (%)	Trust (%)	n
Trust in Providers	20.00%	28.00%	52.00%	25

25 participants contributed adequate narrative for these researchers to code for trust in providers. The majority of participants (who contributed adequate narrative regarding trust/mistrust) demonstrated predominant feelings of trust towards providers. 80% demonstrated either trust or mixed trust, and 20% demonstrated predominantly mistrust towards providers.

Table 8: Descriptive Statistics for Hope (n=34)

Coded Variable	Hopeless (%)	Mixed(%)	Hopeful (%)	Not enough information (%)
Hope	8.82%	32.35%	11.76%	47.06%

Table 9: Descriptive Statistics for Hope (Participants With Adequate Narrative) (n=18)

Coded Variable	Hopeless (%)	Mixed (%)	Hopeful (%)	n
Hope	16.67%	61.11%	22.22%	18

Eighteen participants contributed adequate narrative for these researchers to code for participant hopefulness. The majority of participants who contributed adequate narrative responses demonstrated predominantly mixed hopelessness and hopefulness. There was a 38.89% difference between the mixed and hopeful variables. Participants demonstrated hopefulness 5.55% more than hopelessness.

Table 10: Descriptive Statistics for Connection to ServiceNet and Providers (n=34)

Coded Variable	Disconnected (%)	Mixed(%)	Connected (%)	Not enough information (%)
Connection to ServiceNet and ServiceNet Providers	8.82%	32.35%	35.29%	25.53%

Table 11: Descriptive Statistics for Connection to ServiceNet and Providers (Participants With Adequate Narrative)(n=26)

Coded Variable	Disconnected (%)	Mixed (%)	Connected (%)	n
Connection to ServiceNet and ServiceNet Providers	11.54%	42.31%	46.15%	26

Twenty six participants contributed adequate narrative responses for these researchers to code for participant connection to ServiceNet and ServiceNet providers. The majority of participants who contributed adequate narrative responses demonstrated primarily feelings of connection to ServiceNet and ServiceNet providers. A total of 88.46% demonstrated either mixed feelings of connection/disconnection or predominantly connection. Of codable participants, 3.84% more felt connected than mixed connected/disconnected. Of codable participants, 34.61% more demonstrated feelings of connection than feelings of disconnection.

Table 12: Descriptive Statistics for Narrative Coherence (n=34)

Coded Variable	Incoherent (%)	Mixed(%)	Coherent (%)	Not enough information (%)
Narrative Coherence	11.76%	29.41%	26.47%	32.35%

Table 13: Descriptive Statistics for Narrative Coherence (Participants With Adequate Narrative) (n=23)

Coded Variable	Incoherent (%)	Mixed (%)	Coherent (%)	n
Narrative Coherence	17.39%%	43.48%%	39.13%	23

Twenty three participants contributed adequate narrative for these researchers to code for narrative coherence. The majority of participants who contributed adequate narrative were coherent in some parts but not others. Participants were coded for mixed coherence 4.35% more than predominant coherence. Of codable participants, 82% demonstrated narrative coherence in either half or all of their narrative contributions.

Table 14: Descriptive Statistics for Self-Compassion (n=34)

Coded Variable	**Self Judgment/Self Condemning (%)**	**Mixed(%)**	**Self Compassion (%)**	**Not enough information (%)**
Self Compassion	17.65%	20.59%	8.82%	52.92%

Table 15: Descriptive Statistics for Self-Compassion (Participants With Adequate Narrative) (n=16)

Coded Variable	**Self Judgement/Self Condemning (%)**	**Mixed (%)**	**Self Compassion (%)**	**n**
Self Compassion	37.50%	43.75%	18.75%	16

Sixteen participants contributed adequate narrative for these researchers to code for self-compassion. These researchers were unable to code for self-compassion for more than half of the participants. The majority of participants who contributed adequate narrative demonstrated primarily mixed self-judgmental/self-condemning and self-compassionate tendencies. The next most frequent theme was self-judgmental and self condemning tendences, with 6.25% less participants than the mixed narratives. Less than ⅕ of participants demonstrated self-compassion.

Table 16: Descriptive Statistics for Self-Pathologizing (n=34)

Coded Variable	**Self Normalizing (%)**	**Mixed(%)**	**Self Pathologizing (%)**	**Not enough information (%)**
Self Pathologizing	17.65%	14.71%	11.76%	55.88%

Table 17: Descriptive Statistics for Self-Pathologizing (Participants With Adequate Narrative) (n=15)

Coded Variable	**Self Normalizing (%)**	**Mixed (%)**	**Self Pathologizing (%)**	**n**
Self Pathologizing	40.00%	33.33%	26.67%	15

Fifteen participants contributed adequate narrative for these researchers to code for self-pathologizing themes. These researchers were unable to code for self-pathologizing for more than half of the participants. The majority of participants who contributed adequate narrative demonstrated primarily self-normalizing tendencies. 6.66% less demonstrated mixed tendencies. The theme coded with the least frequency was self-judgmental and self condemning tendences, with 6.25% less participants than the mixed narratives. Only 13.33% more participants demonstrated self-compassionate patterns than self-condemning patterns.

Table 18: Descriptive Statistics for Self-Trust (n=34)

Coded Variable	**Self Mistrust (%)**	**Mixed(%)**	**Self Trust (%)**	**Not enough information (%)**
Self Trust	5.88%	29.41%	23.53%	41.18%

Table 19: Descriptive Statistics for Self-Trust (Participants With Adequate Narrative) (n=20)

Coded Variable	**Self Mistrust (%)**	**Mixed (%)**	**Self Trust (%)**	**n**
Self Trust	10.00%	50.00%	40.00%	20

Twenty participants contributed adequate narrative for these researchers to code for self trust. The majority of participants who contributed adequate narrative demonstrated primarily mixed self trust and self mistrust. 10% less participants demonstrated self-trust. A total of 90% of codable participants demonstrated either mixed trust/mistrust or predominant self-trust. Interestingly, 30% more participants demonstrated self trust than self mistrust. Ten percent of codable participants demonstrated self-mistrust.

Table 20: Descriptive Statistics for Locus of Control (n=34)

Coded Variable	Internal(%)	Mixed(%)	External (%)	Not enough information (%)
Locus of Control	11.76%	29.41%	20.59%	38.24%

Table 21: Descriptive Statistics for Locus of Control (Participants With Adequate Narrative) (n=21)

Coded Variable	Internal (%)	Mixed (%)	External (%)	n
Locus of Control	19.05%	47.62%	33.33%	21

21 participants contributed adequate narrative for these researchers to code for locus of control. The majority of participants who contributed adequate narrative demonstrated primarily mixed locus of control. The next most frequent theme was external locus of control, with 14.29% less participants than the mixed narratives. Less than 1 out of 5 participants demonstrated an internal locus of control.

Table 22: Descriptive Statistics for Congruence between Quantitative and Qualitative Responses (n=34)

Coded Variable	Congruent(%)	Not Congruent (%)	Not enough information (%)
Congruence	46.42%	17.14%	66.59%

Table 23: Descriptive Statistics for Congruence between Quantitative and Qualitative Responses (Participants With Adequate Narrative) (n=24)

Coded Variable	**Congruent %**	**Not Congruent %**	**n**
Congruence	85.71%	14.29%	24

Twenty four participants contributed adequate qualitative data for these researchers to code for congruence between quantitative and qualitative responses. The majority of participants who contributed adequate narrative demonstrated primarily congruent responses (85.71%). These researchers also coded for non-congruent responses (14.29%).

Correlation and Regression Analyses. The survey yielded primarily nominal data, and thus the results are descriptive. These researchers consulted with Marjorie Postal, Research Analyst at the Smith School for Social Work and ran several types of analyses for the following variables and were unable to find statistically significant correlations. These researchers ran Spearman rho correlations to determine if there was a relationship between hope and connection, or between hope and self compassion. Lehman (2005) defines a *Spearman rho correlation* as a nonparametric measure of statistical dependence between two variables. A *crosstab* was run that broke down race by trust of others. However, there was no statistical test that could be used given that the majority of the sample identified as white (71%) and the two remaining groups were too small to find statistically significant results. These researchers ran a *Spearman rho correlation* to see if there was a relationship between age and locus of control.

These researchers ran a *crosstab* to examine the breakdown of locus of control and age. For gender, these researcher removed the 1 non-binary person and compared only male and female participants. These researchers then conducted *crosstabs* to investigate the breakdown of self-compassion and self-pathologizing by gender (male/female). Following the crosstabs, these researchers also ran a *t-test* to see if there was a difference in self compassion and self pathologizing by gender (male/female). As stated previously, no statistically significant results were uncovered during any of the secondary analyses of these data.

CHAPTER VII

Discussion

Introduction. ***Summary of Project.*** These researchers utilized Participatory Action Research (PAR) to design a program evaluation for ServiceNet's Mental Health Recovery Services (MHRS). These researchers sought to explore to what degree MHRS program participants feel ServiceNet supports them to meet their own self-defined needs and goals.

MSW candidate researchers Margot Reilly, Heather Crawford, and Caroline Evans met weekly for the duration of the project, and were joined once every two to three weeks by research adviser Seth Dunn LICSW. The 2015-2016 academic year was the first year Smith College School for Social (SSW) Work allowed group thesis projects and researchers were in ongoing dialogue to follow new thesis requirements. Researchers navigated a tension between adhering to the principles of PAR while navigating tangible constraints of their master's level thesis requirement. These researchers utilized in-person discussion in order to come to agreement about any issues where there was disagreement.

These researchers held two focus groups with ServiceNet Peer Counselors, and one focus group at the Recovery Learning Community (RLC, an external organization.) These researchers faced divergence between RLC and ServiceNet focus group findings. In the face of major ideological divergence, researchers defaulted to the ServiceNet focus group's conclusions due to their inner-organization positionality. Further, the RLC focus group's idea for a narrative interview project facilitated by external agency peers presented significant feasibility challenges due to confidentiality concerns. These researchers brought all of the findings from the RLC focus group to the second ServiceNet group for discussion, and the second ServiceNet focus group incorporated the RLC focus group findings into survey question development though retained the original agreed-upon mixed-methods survey structure. Both ServiceNet and RLC focus groups agreed that they would like to collaborate further in the future.

ServiceNet Focus group participants and researchers explored a variety of program evaluation modalities and ultimately agreed upon on a mixed methods survey delivered by ServiceNet Recovery Counselors to ensure project feasibility, enable greater participant engagement, foster evaluation reproducibility, and generate reputable results to evaluate participant satisfaction and identify areas for improvement of participant experiences. These researchers engaged in dialogic and collaborative processes with focus group members to generate survey format, determine optimal logistics of data collection, prioritize and select survey questions, and troubleshoot potential accessibility barriers.

Surveys were delivered to 102 randomly selected MHRS program participants by Recovery Counselors. Twelve surveys were refused and returned unopened, 56 program participants received the survey envelopes and did not return them, and 34 surveys were returned completed. Survey data was entered into Survey Monkey by ServiceNet supervised Smith College undergraduate psychology interns, and these researchers only had access to aggregate and de-identified data. These researchers only had access to demographics of participants who completed surveys, and did not have access to the demographic data of the sample of 102 participants randomly selected participants that the survey was sent out to. Unfortunately, these researchers could not compare response rate between different demographic variables. See Discussion *Chapter VII: Limitations* for further elaboration on the sample limitations and limitations of data analysis. See *Findings Chapter VI: Table 1* for more information about the research sample.

These researchers collaboratively analyzed both the quantitative and the qualitative data. Descriptive statistics were generated through Survey Monkey. Caroline Evans collaborated with Marjorie Postal to run secondary analyses, all of which yielded inconclusive and statistically insignificant results. These researchers collaboratively determined and defined coding categories for qualitative analysis, and then coded 25% of the participants for each category to determine inter-rater reliability, reduce bias, and adhere to APA standards. These researchers then each coded one third of the remaining participants for all variables. Margot Reilly completed tables 1-21 and associated narratives. Caroline Evans and Heather Crawford competed tables 22 and 23 and associated narrative. Each researcher authored one chapter of the literature review. Caroline Evans and Margot Reilly co-authored the methodology section. For Discussion Chapter VII; Margot Reilly authored this Introduction and associated subsections, Heather Crawford authored the Limitations and Ethical Concerns sections, and Caroline Evans authored Bias and Implications sections.

Summary of Sample. The total sample was comprised of 34 participants. Most of the participants were from ServiceNet's Hampshire MHRS Teams 1, 2, and 3. There were no participants from Team 5. These researchers opted to provide a fill-in-the-blank box for participants to identify their race using their own terminology. In order to run statistical analyses on the data, researchers had to group participants into four categories. The racial makeup of survey respondents included 8.8% People of Color identified, 2.9% Multi-racial identified, 70.6% White identified, and 17.6% Unknown or No Response. To preserve anonymity, respondents were asked to check a box with their age range and 0% identified between 21-29, 47.1% identified between 30-45, 35.3% identified between 46-60, 14.7% identified as 61 and older, and 2.9% of respondents were of unknown age. No one in the sample was under the age of 30. In the future, with a larger sample size, these researcher recommend pursuing a stratified random sample to enable regression analyses and greater representation of demographic variables including race, gender, and team membership.

Interpretation and Summary of Quantitative Findings. These researchers sought to evaluate if MHRS program participants feel supported by ServiceNet to meet their own self-defined needs and goals. In ongoing dialogue with focus groups, the survey tool was developed to evaluate participant experience of voice in treatment, relationships to providers, education about rights and resources, staff training, and self-advocacy.

The first survey question asked participants to mark all needs that they feel are met by ServiceNet. Due to the structure of this question, these researchers cannot determine what the absence of a check signifies. For example, only three participants marked that ServiceNet is meeting their spirituality needs. It is unclear whether the remaining 31 participants do not identify spirituality as personal need. Further empirical exploration of the nature of ServiceNet program participant needs and values may help clarify the significance of these findings.

The four needs that participants marked as met with the most frequency were housing, personal growth, emotional support, and transportation. These researchers believe housing to be a fundamental human right, and thus feel it is important that participants seem to feel mostly supported around their housing needs. While housing was the need marked as met with the most frequency, 32.45% of participants did not mark this need as met. As previously mentioned, the true significance of these findings is difficult to determine-- question structure does not clarify if this 32.45% does not need support to secure safe housing or if they do need support and aren't being supported adequately. Similarly, for personal growth and emotional support, these researchers noted that these central needs were marked at relatively high rates. Still, 38.24% of participants did not mark personal growth as a need met by ServiceNet, and 41.18% did not mark that ServiceNet meets their need for emotional support. ServiceNet's transportation support system has been evolving in recent years, thus it may be significant to ServiceNet that participants seem relatively satisfied with these supports; 55.88% of respondents marked this need as met.

The four needs that were identified as met with the least frequency were legal support, educational, employment, and spirituality. Due to these researchers positionality outside of ServiceNet, these researchers are unable to comment definitively on these findings' implications for ServiceNet administrative objectives. These findings indicate that ServiceNet program participants may benefit from greater legal, educational, employment, and spiritual support. It is unclear whether or not ServiceNet seeks to support participants in legal, educational, and spiritual matters. ServiceNet reports that DMH has been emphasizing employment programs in recent years, thus findings may illuminate a need for further evaluation of employment support services. Other needs that were marked as notably low include the need for physical safety and the need for social connection, both arguably fundamental and universal human needs that yielded less than 50% affirmative responses.

Adjusting for the more complicated format of Questions 1, 10, and 13, participant satisfaction ranged from 62.07% to 90.32% depending on the variable. Participants report the highest levels of affirmative responses around feeling treated like a human being, feeling that they have enough information from their medication providers, feeling that staff care about them, and feeling that staff are well-trained enough to meet their service needs.

Participants report the lowest level of affirmative responses around feeling informed to make a human rights complaint and feeling heard if they report dissatisfaction with their services. A significant minority (34.36%) of respondents report feeling either uncertainty about whether they be heard or certainty that they won't be heard if they report dissatisfaction with their services. Significant numbers (37.93%) of respondents report that they are either unsure of how or do not know how to make a human rights complaint. ServiceNet policy stipulates that each new program participant receives verbal and written orientation on human rights and each program has a designated human rights officer who is intended to be known to all participants. Findings may illuminate a need for more ongoing education about the process of filing a human right's complaint, refining of the human rights education materials and examining of their accessibility, and/or further empirical exploration of policies and practices related to participant self-advocacy rights and processes.

The question with the lowest rate of affirmative response was whether or not participants were given the option to discuss a plan to graduate from the program if they want one. Only 34.38% of participants responded that they were given the option, 31.25% selected that they were not, 15.63% were unsure, and 18.75% felt the question was not applicable to them. A contributing factor to the low affirmative response may be respondent confusion due to the different format of this question from the others. Further empirical exploration of MHRS participant perception of graduating from the program may be helpful to illuminate the low levels of affirmative response. These researchers wonder if there may be a connection between low levels of hope (22.22% coded as hopeful) demonstrated in qualitative responses and the fact that the majority of participants (65.42%) responded that a plan to graduate was either not applicable to them, they have not been given one and want one, or are unsure if they want or have been given a plan to graduate.

Focus group members unanimously agreed that the nursing schedule is often inhibitory of participant daily activities, and felt strongly that a question be included in the survey to empirically demonstrate this issue. One in four (25%) of survey respondents report that the nursing schedule does not work well with their daily routine. This relative dissatisfaction may stem from inadequate staffing and/or structural issues in need of further exploration. It is unclear whether or not this level of satisfaction/dissatisfaction is significant enough to merit organizational structural change within ServiceNet. While these researchers anticipated greater levels of dissatisfaction, these researchers assert that 25% dissatisfaction with a fundamental support for life engagement merits further organizational inquiry and exploration.

Interpretation and Summary of Qualitative Findings. These researchers coded for the following variables; trust in providers, hope, connection (to ServiceNet and ServiceNet providers), narrative coherence, self compassion, self pathologizing, self trust, locus of control, and congruence between qualitative and quantitative responses. These researchers initially convened to operationalize and establish joint definitions of each variable. These researchers then independently coded all variables for the same 25% of respondents, and subsequently reconvened to determine inter-rater reliability and establish consensus. Once these researchers established at least 85% consensus for each variable, the remaining 75% of respondents were divided evenly and researchers coded each variable for their designated participants.

Depending on the variable, these researchers were able to code between 15 and 26 participants who contributed adequate narrative relevant to the variable in question. These researchers were able to code the greatest amount of participants (n=26) for connection (to ServiceNet and ServiceNet providers). The variable that researchers were able to code for fewest participants for the self-pathologizing variable (n=15).

Qualitative analysis demonstrates high levels of connection to ServiceNet and ServiceNet providers; 88.46% of codable participants demonstrated either signs of connection or signs of mixed connection/disconnection, and only 11.54% of codeable participants demonstrated predominantly signs of disconnection with providers. The qualitative connection findings demonstrate significant positive connection between program participants and providers, and are perhaps connected to quantitative findings that demonstrate high levels of positive response for the following variables; 80.65% of respondents answered that they feel staff care about them and 90.32% of participants marked that they feel they are treated like a human being.

In contrast however, only 44.12% of participants marked that their need for social connection as met by ServiceNet. Perhaps further evaluation of participant sources of human connection may illuminate an area of growth for ServiceNet to build upon the organizational strength of generating interpersonal connection with providers to foster greater community and social connections for participants as well.

Hope (22.22%) and self-compassion (18.75%) are the qualitative variables that were coded with the least positive frequency. As mentioned previously, these researchers wonder about the connections between hope and the low quantitative results around attainability of program graduation and self-advocacy. These researchers also wonder if the relatively low levels of feeling informed about human rights complaints (62.07%) and relatively low levels of participants who feel they will be heard if they are unsatisfied with their services (65.63%) might be contributing to low levels of hope demonstrated in qualitative findings. These researchers also wonder if low levels of hope may be a result of the prevalence of depressive symptoms among program participants.

These researchers also wonder about the connection between the low levels of hope and the self-pathologizing, self-compassion, and self-trust variables. Approximately one-in-four (26.67%) participants demonstrated predominantly self-pathologizing attitudes and beliefs. While (40.00%) of codeable participants demonstrated predominantly self-normalizing beliefs and attitudes, the majority of participants demonstrated at least some self-pathologizing attitudes and beliefs; 60.00% of participants were coded for either mixed self-pathologizing or purely self-pathologizing beliefs/attitudes. For the self-compassion variable, less than one-in-five (18.75%) of participants demonstrated predominantly self-compassionate beliefs/attitudes. In regards to trust, the majority of participants (60.00%) demonstrated either predominantly self-mistrust or mixed self-trust/self-mistrust.

The qualitative findings around low levels of hope, high levels of self-pathologizing, low levels of self-compassion, and low levels of self-trust may indicate a need for more ongoing work to further externalize internalized inferiority and oppressive narratives among ServiceNet clients. Further, due to the legacy of disempowering cultural narratives around mental health differences, these researchers were also unsurprised to find that the minority of participants

(19.05%) demonstrated predominantly internal locus of control. Despite a culture of individualism, these researchers wonder if the legacy of dependency promoting, paternalizing narratives around mental health differences may be contributing to beliefs that participants do not know what's best for themselves.

Research illuminates that ServiceNet is clearly doing important person-centered work and effectively responding to and meeting participant needs while forming positive relationships with participants. Research also indicates a need for ongoing examination of ServiceNet culture and policies that might be inadvertently perpetuating or failing to actively subvert ableist narratives. Research illuminates a need to foster greater ServiceNet participant sense-of-agency and personal hope. Exploring potential barriers to participant self-advocacy (through human rights training and organizational responsiveness to participant dissatisfaction), may be a concrete area of further exploration for ServiceNet to continue to cultivate empowering and person-centered practices.

A central question these researchers held throughout the PAR and survey implementation process was survey accessibility. A central limitation of the paper survey is that it requires literacy skills. These researchers are unable to obtain information about the participants who received the survey and either did not complete it or refused to complete it, and thus can only complete analyses on the completed surveys.

The coded variables for narrative coherence and congruence between quantitative/qualitative responses may illuminate accessibility challenges for the participants who responded. The majority of participants (60.87%) who contributed adequate narrative to code for coherence (n=23) either demonstrated mixed levels of coherence or predominantly “incoherent” (to these researchers) responses. The vast majority of participants (85.71%) however, demonstrated congruence between quantitative and qualitative responses. The high congruence data may signify high survey comprehension and thus signify greater accessibility. These researchers are concerned by the coherence findings, and acknowledge that important content certainly has been missed due to these researcher’s comprehension challenges. Further, these researchers wonder if potential accessibility challenges may have been a barrier for participants who did not contribute narrative and only provided quantitative responses. These researchers suggest future empirical engagement around the refused and unreturned surveys to further evaluate accessibility challenges.

Limitations. These researchers had many objectives at the start of this project. Although these researchers had set out to discover the self-defined needs of the participants at ServiceNet and whether these needs were being met, many limitations were encountered along the way. This section outlines the limitations of our research and the process by which these researchers made decisions given these limitations.

There were factors from the beginning which these researchers knew would limit the scope of the project, such as our choice of methods. However, there were also unexpected obstacles which were dealt with as they arose. Specifically, these researchers encountered limitations with the practicality of actually executing the type of project these researchers were interested in doing, with the sample, with the quantitative data, and with the qualitative data. After the limitations, the ethical concerns and biases these researchers had along the way follows in the subsequent sections.

These researchers' objectives and process included using the PAR method in order to investigate whether or not ServiceNet participants' needs were being met. We also utilized in person discussion to settle any disagreements these researchers had along the way. The limitations we came across in this process included having very limited time and resources. On top of this thesis project, these researchers were also spending 30 plus hours per week at unpaid internships in addition to doing required readings up to six hours per week. These researchers also had only from September until April to complete the bulk of the thesis work, limiting the scope of our investigation significantly. For example, these researchers were unable to investigate the perspectives of counselors and family members of the participants in order to get a fuller view due to the small scope. In addition, ServiceNet has only limited funding to dedicate to such projects. These researchers also had to contend with scheduling difficulties in order for four individuals to meet once a week, additional obligations such as internship commute time, and deadlines that the Smith College School for Social Work imposed as well.

The focus group process had limitations as well. Due to confidentiality and privacy concerns, these researchers were unable to meet with the ServiceNet focus group members and the RLC focus group members all together. In addition, due to scheduling difficulties, the original focus group members were not all available for the second focus group. Also, these researchers were unable to continue analysis with the RLC due to these researchers' inability to reconcile ideological divergence about how the study should proceed, a further complication of the above mentioned limitation of not being able to meet all together to preserve confidentiality.

Another limitation which impacted this research was these researchers' relative lack of experience. These researchers are students and thus have limited training, social status and power within an agency setting and at the educational institution. These researchers are still in the process of developing their own clinical styles and voices and well as foundational understandings of statistics. Perhaps if this study is replicated, researchers could enlist someone who is more knowledgeable in statistics to provide some sort of research training for the participants (and researchers) who were involved in designing the study, so that they can benefit from knowledge about statistics and academic “expertise” and the results from such a study may be less affected by a potential “expert bias” assuming that the “expert bias” is caused in part by uneven distribution of privileged education between researchers and participants. This way, a statistics training for both may bridge a gap and assist in maintaining the commitment to social justice, as the participants benefit from the project as well.

One limitation related to the PAR method that these researchers selected for this study involves what the participants know and do not know about why their needs are or are not being met. These researchers wanted to do this research in a way which honors person-centered treatment evaluation, and this limits the role that the researchers play in order to center the voices of the participants. While this has been beneficial in many ways (for example, tipping the power balance toward participants), the researchers’ limited role in conducting the research may have occluded potentially important factors to look at when evaluating an agency program.

For example, the focus group participants did not have knowledge about the agency’s budget, managed care insurance information, caseload expectations for counselors, etc. and so they could not include these as factors to evaluate when doing the program evaluation. The internal affairs, policies, and practices of the agency seem likely to have an enormous impact on the care that the participants receive, but the participants’ relative lack of knowledge about these issues may have kept these items off the table as potential areas to research. Thus, future researchers may want to collaboratively work in the evaluation of systemic factors in addition to learning about the subjective experiences of participants.

Limitations of the Sample. The sample for this study has many limitations. The sample did not include anyone under the age of 30. The majority of participants were from teams 1, 2, and 3 and did not include anyone from team 5, limiting the generalizability of the sample. In addition, the DMH survey which provided population data did not include a category for non-binary gender so that information was not collected, disallowing these researchers from determining whether or not our sample was representative. Also, these researchers chose to ask about racial identity using a fill-in-the-blank, which created problems due to spelling errors and confusing responses which were difficult to then collapse across categories in order to allow for meaningful statistical analyses. Most participants were between 30 and 45 years of age, which was close to expectable, though the population data indicates that the entire population of ServiceNet participants is slightly older (between 46 and 60 years of age). Another possible limitation of this sample is that our small sample size did now allow for us to find any significant results for correlational and regression analyses even if these researchers had used interval or ratio data rather than nominal/categorical data.

Quantitative Limitations. This study also included limitations regarding how we asked and framed the survey questions as well as how we devised our survey tool. For example, these researchers did not have much time to test the reliability and validity of our survey tool. In addition, these researchers were dismayed to find the low rates around graduating from the program and were curious about how this might connect to levels of hope versus the wording that was chosen (i.e. “recovery” versus “graduation”). These researchers also felt that the question about how to make a human rights complaint could have been more specific, such as asking the participants to actually write out the steps to ensure that they truly did know the agency’s protocol versus complaining to a staff informally. In the needs meeting check-box question, the main limitation was that these researchers could not determine whether the unchecked needs were unchecked because the participant indeed had a need and it was not being met or if they did not personally have that particular need at all (such as spirituality). Since many needs are not universal, there are implications for future research which will be covered in the next section.

Another limitation of the current study involves the potential connections between the quantitative questions as well as what can be inferred from the results. For example, although the majority of participants felt they are being treated like human beings, the majority did not feel informed about how to make a human rights complaint. Due to these researchers asking the questions the way they were asked, it is unclear how the answers to these questions might relate to one another. Another limitation includes the fact that our data was nearly all nominal or categorical in nature, preventing us from doing certain quantitative statistical analyses which would allow us to infer more about the entire ServiceNet population and understand the relationships between different variables that researchers asked about such as the relationship between age and locus of control, which these researchers were curious about especially considering the impact of deinstitutionalization on some of the older participants’ lives.

Qualitative Limitations. Due to time limitations, these researchers had limited coder training both prior to and during this project. In addition, these researchers were unsure of how to test for reliability and validity for qualitative data, aside from the small coder training and interrater reliability check that these researchers completed. Therefore, these researchers felt that should this pilot project be replicated, there are implications for future research regarding reliability and validity.

The coding for the narrative coherence variable had limitations as well. Most participants were coded as coherent for some of their narrative but coded as incoherent in other spots of their narrative. This likely biased the results and the conclusions that can be drawn from them because there is no way to know if something these researchers felt was coherent was actually meant by the individual or vice versa. Something these researchers felt was incoherent may have reflected an idea that really makes sense for the person who wrote it, though these researchers failed to comprehend it. Language and communication clearly have a very large impact on recovery and treatment and vice versa as well. How can this be better evaluated in the future?

Related to narrative coherence, language, and communication, another limitation to this study is that these researchers used a paper survey, requiring participants to be literate in order to be included in the study. However, the focus group attempted to word the questions in such a way to make it easier for readers/writers of most levels of literacy to be able to participate, by choosing not to use language which may be too academic or intimidating to participants who struggle with reading and/or writing. Further complicating this caveat, many participants may or may not have been experiencing symptoms, cognitive impairments, and/or side effects of long term medications which may have been impacting their ability to complete the survey in such a way that accurately portrays their true needs, feelings, and opinions. Future researchers may want to incorporate some kind of mental health status exam immediately prior to their taking the survey in order to ensure that symptoms are not biasing their answers.

In addition to this, the qualitative data was also limited by the nature of the data collected. Because these researchers used nominal (categorical) data and only three or four categories for most of the variables, the findings were mostly descriptive rather than allowing us to infer much about the population or about the relationship between variables using statistics. However, these researchers feel that this descriptive information may lay a good foundation for future research, as will be described in subsequent sections.

Ethical Concerns. These researchers encountered many ethical concerns and dilemmas as the research proceeded along. These include ethical concerns around maintaining honest disclosure and transparency, consent, conflicts of interest, privacy and confidentiality, and maintaining social justice (particularly racial, economic, disability, and human rights justice).

One ethical concern these researchers encountered involved the survey participant letter, which was meant to enhance consent by providing honest disclosure and transparency about the nature and objectives of the research project. These researchers wished to convey what the survey was, who was involved in creating it, and how participants' information would be handled. There was however, an oversight in the writing of the letter; it was unintentionally not disclosed to the survey participants that Seth Dunn LICSW was involved with the project. Fortunately, these researchers used a double-blind procedure, so the participants' information was not identifiable for Seth Dunn LICSW or for any of these researchers.

In addition, there were a couple of potential conflicts of interests which were ethical concerns of ours as well. This researcher, Heather Crawford, was employed at ServiceNet for seven years prior to the beginning of this project. There were three years in between the end of this writer's employment period and this writer's involvement with the current research project. Although it is possible that this conflict of interest may have skewed the results in some way, the research team worked together in order to minimize the potential damage of this overlap as well as maximize the beneficial effects of the overlap in experience. For example, one participant saw this writer's name on the survey participant letter and directly addressed this writer in their narrative response. The team decided that this writer would not read that participant's responses in order to maintain confidentiality and professional distance. In addition, this writer attempted to use continuous self-reflection throughout the process and focus on ways in which this prior work experience could help rather than hinder our aims (such as by making suggestions for the survey during the focus group based on experiences with participants in the past, such as when many people mentioned to this writer that the medication delivery schedule was inconvenient for them). This writer recognizes the privilege that comes along with having that prior experience as well as the ways it may bias the study results, as will be discussed in the next section on bias.

These researchers were concerned with the ethical commitment to maintain privacy and confidentiality and this expressed itself in a few different ways during the process. For example, these researchers decided to use a double blind study procedure in order to improve privacy and confidentiality. In addition, these researchers decided not to include the full, actual survey results in order to prevent any identifiable information from inadvertantly being shared when the final paper is posted. Also, during the focus groups and in the survey participant letter, these researchers expressed the need for privacy and confidentiality for all involved.

Finally, these researchers and many of the focus group participants had and discussed ethical concerns around maintaining social justice throughout the project, including economic and class justice, racial justice, disability/neurodiversity justice, and justice around human rights and third party impartiality. For example, the RLC focus group members felt that participants should have been paid minimum wage for the time they spent filling out the survey, or at the very least more than the $2 that we were able to offer as compensation. Although these researchers agreed with this view, there were financial limitations to what could be offered that these researchers could not control. However, these researchers advocated for an increase from the original $1 to the $2 that was settled on for compensation as a result of this issue.

In addition, the RLC focus group participants also felt that human rights incidents should be handled by third party agencies at all times throughout the human rights complaint process. The current policy at ServiceNet states that human rights violations are legally to be reported to a third party agency, as the Human Rights Committee legally *must* include multiple third parties, including community members who are not affiliated with the agency that the HRC oversees. However, parties within the agency are sometimes involved, such as the human rights officers who are legally required to work at each site.

Lastly, these researchers felt that there was an ethical problem with categorizing participants' races in order to test whether or not there were differences in need satisfaction by racial identity. These researchers felt that although labeling others' races is ethically problematic, it would have been *more* ethically harmful to *not* attempt to discover whether or not those who identify as being a member of an oppressed racial category are having a different experience (for example, their needs are being met even less) than those of a privileged racial category. These researchers all identify as being members of a privileged racial category, white/European American, and feel it is important to recognize the potential ethical impact of white privilege on attempting to study racial injustice in this study.

Bias. The ServiceNet Participatory Action Research Program Evaluation would not be complete without an examination of researcher bias. The acknowledgement of researcher bias is relevant to this program evaluation because the identity of the researcher influences how the researcher interprets results. These researchers were working with people who are described by ServiceNet as having “mental illness and other disabilities” (ServiceNet History, n.d.) People who are perceived as disabled are subject to a multitude of different types of discrimination. This is apparent when we look at the language of “illness” used in American culture to describe mental health challenges. As these researchers were born and raised in the United States of America, it would be impossible for these researcher’s opinions not to have been impacted by structural ableism (Rothman, 2003).

Another bias may originate from interpreting survey data through the lens of social workers. Social workers are commonly referred to as “helping” professionals. The social worker lens creates irony because it assumes that the people that these researchers were working with asked for help. Ultimately, it was other social workers who were part of ServiceNet that were asking for assistance. Further, as MSW candidates, these researchers’ time limitations and thesis requirements continually defined the scope and nature of the project. This dynamic continues to privilege the voice of the social worker over the voice of the participant effectively continuing a cycle of disempowerment. Thus, these researchers may have perpetuated a power dynamic in some aspects of the research, while intending to subvert it.

One potential way for future social work researchers to avoid this all too common pitfall could be to focus from the outset of the project on the specific policies of the programs, agency, educational institution, and funding sources of the agency which directly affect both treatment and evaluation of treatment. In order to truly do anti-oppressive work, future researchers evaluating this agency should identify the funding source(s) and obtain insurance information and identify areas for improvement within that system, in addition to focusing on participants' need satisfaction and subjective experience. These researchers suggest that future researchers make intersectional, *systemic* anti-oppression a high priority during the *early* stages of developing the research project, rather than attempting to fold it in mid-way through.

For example, ServiceNet's current structure employs both "mental health counselors" (wellness counselors and recovery counselors) as well as "peer counselors" and the peer counselors are paid at a lower rate. Perhaps ServiceNet's policies have yet to catch up with the relatively recent research which places a higher emphasis on intersubjectivity and lived experience than on academic or scientific knowledge, which would suggest that equal pay for counselors and peer counselors would be appropriate, not to mention that some of the counselors who were not hired as "peer" counselors may also have lived experience with mental health issues, regardless of their academic and work experience.

In addition to adopting anti-oppressive therapeutic frameworks, these researchers recommend examination of existing policies that may be inadvertently contributing to a greater difference in the power dynamic between participants and staff. For example, these researchers encountered a policy that states that volunteers and employees who currently smoke cigarettes will not be hired and applicants must sign an agreement stating that they do not currently smoke.

While it seems that the policy intends to reduce negative role modeling effects of staff who struggle with nicotine addiction on participants who also struggle with the addiction, these researchers wonder if it may have unintended negative effects for both staff and participants. For example, there is a value-judgment about nicotine addiction embedded in the policy that may further pronounce power dynamics between participants and staff. In the context of anti-oppression frameworks, given that the incidence of nicotine addiction is much higher among people who are from lower income backgrounds (Sanderson, 2004), this policy would likely discriminate against individuals from lower class backgrounds, as well as some of those with lived and subjective mental health experiences. These researchers recommend ongoing examination of policies and practices that may create incongruence with the ServiceNet's mission and values.

The question remains for these researchers, "who benefits from this research?" As social workers, these researchers are fulfilling a responsibility to evaluate ServiceNet's MHRS program. While these researchers are not direct stakeholders in the agency, these researchers were advised by Seth Dunn LICSW, an employee at ServiceNet. He examined his bias throughout the project, though these researchers acknowledge the possibility of implicit bias to find assurance that the organization is following through with their mission to provide opportunities and social justice to the population with whom ServiceNet works. However, once evaluated, will the findings of this research ultimately speak for themselves. However the question remains, will this project influence change or will this project simply serve to create an appearance of agency that is socially conscientious?

Intersubjectivity. The intersubjectivity of these researchers created bias as well. One of these researchers had previously worked at ServiceNet and felt, as a former counselor, there was a conflict of interest. Although not an active stakeholder, this researcher felt that this previous work experience both negatively biased this researcher's perspective in many ways and enhanced this researcher's empathy and understanding of ableism, expert bias, and other concepts which are important in social work. First, as a former worker, this researcher felt at times unnecessarily defensive about staff at the agency, which could have thwarted our evaluation efforts had the team not addressed this issue. Secondly, this writer felt that being familiar with some of the focus group members and having more "insider" knowledge about the agency was also beneficial at times as well, particularly during the first focus group.

Another researcher had also worked as a peer counselor in the past. This researcher felt that their experience contributed to their perception of ableism. Past experience contributed to the questions these researchers posed during this project in their discussions, however ultimately these researchers approached this project with an attitude of "not knowing" (Anderson, 2001).

Interpersonal relationships between ServiceNet staff and participants may have also been treated in a biased way. Individual interpersonal relationships may have inhibited survey participants from completing the survey. For example, these researchers intended to have the surveys distributed by Recovery Counselors who were considered by the peers in the focus groups to be "trusted staff." However, based on the theory of intersubjectivity, it can be gauged that each participant and their Recovery Counselor would bring unique characteristics into specific counseling relationships (Scheff, 2006). Assuming that Recovery Counselors were unanimously “trusted” may have been a bias that contributed to the number of survey refusals these researchers received.

Implications for future research. ***Time.*** These researchers could have been better able to utilize PAR in its truest form had the team been able to extend this project beyond the September 2015 to April 2016 timeframe. Essentially, fewer time constraints would have enabled researchers to involve peers in more aspects of the research and conduct in person interviews. With more time, these researchers would also have been able to conduct additional focus groups with peers. These researchers would have benefitted from additional time to work with the peers who participated in the focus groups to provide the peers with more information about research methods. Supplying the peers with more information about research methods could have created a more informed team and could have aided peers in considering which survey questions could produce the most significant results.

Additional time may have allowed researchers to attain survey responses from a wider range of people, or acquire a stratified random sample. This would have allowed these researchers to find more significant results during regression data analysis. More time would also have allowed researchers to conduct more in depth discussions about the findings.

More time could have also allowed these researchers to take a greater role in facilitating a bridge between Recovery Learning Community (RLC) and ServiceNet peers. It was apparent from the responses in the focus groups that both the peers at the RLC and at ServiceNet were interested in creating a stronger alliance. This bridge could support peers and facilitate the planning of continued education for participants around issues of self-advocacy.

Structure. The responses of participants in this study had implications for improvement of the overall structure of future survey tools. Notably, the survey tool created by these researchers and the survey tool created by DMH differed in that the survey these researchers utilized allowed for racial self-identification as well as gender self-identification. The responses of participants to this research team's survey instrument demonstrated that not all participants had identities that conformed to the gender binary, although all DMH program participant demographic data groups participants according to the gender binary. These researchers suggest that DMH allow individuals to self-identify their gender to avoid falsely labeling participants and alienating them.

The responses of participants in this study also had implications for gathering racial demographics of participants in future studies. These researchers felt creating a list of racial descriptions to choose from could have made data analysis more poignant. Initially, the intention of these researchers was to create a format that allowed participants to identify their race as they defined it. However, the variance in responses made data analysis in its original form impossible. Therefore it was necessary for researchers to manually alter participant's responses to fit into an analyzable framework. Although using a preconceived list of choices would limit respondents to specific responses, which would not fit into all participant's visions of their self-defined racial identities, this option would be preferable because it would allow participants to have the final selection rather than the researchers. In order to analyze the data, researchers had to impose their own interpretations of participant racial self-identification. These researchers all identify as white.

Another suggestion for the structure of future survey tools could be that surveys could be structured to use questions that inquired about participant's individual ages as opposed to using questions that asked whether participants age fit into a particular age range. Originally, these researchers felt that if the survey tool gathered information for age ranges instead of specific ages then participants would be less identifiable. While asking participants to identify their age poses a potential threat to anonymity, this change could allow for future researchers to be able to run regression analyses and thus acquire potentially important findings among disparities between different age groups.

These researchers found that it would have been helpful to adjust the random sampling process to ensure representative distribution between teams, race and gender. Again this would have been helpful in assisting with data analysis and may have allowed these researchers to be able to generalize the results of this survey to a wider range of MHRS participants. Future researchers could also adjust the format of the "needs" section in a future survey tool. A revised survey tool could allow participants to indicate that their need was being met, unmet or whether a category was not an area that the participant defined as a need.

Finally, these researchers were left wondering how to decipher the meaning of a relatively high number of survey refusals. Future researchers might want to consider the possibility of further inquiry as to the reasons why program participants refused to even open the survey. This inquiry could be integrated into the survey distribution by providing instructions to Recovery Counselors to ask a question to participants following a survey refusal. This would help researchers to get a clearer sense of whether people refused to fill out the survey due to dissatisfaction, lack of energy, accessibility challenges, lack of hope, or other reasons. This information would also give researchers important information about how the survey refusals may have skewed the findings.

Implications of Quantitative Findings. From the quantitative data, questions 10 and 13 produced findings that have specific implication for ServiceNet. These two questions yielded the highest levels of dissatisfaction. From the responses we received to question 10, these researchers inferred that it would be helpful to have increased dialogue related to the concept of participants graduating from ServiceNet. This is reflected in the quantitative responses to question 13. For question 13, only 42.31% of participants who want to graduate feel that they have been given the option to discuss a plan, while 38.46% of participants who want to graduate feel that they have not been given the option to discuss a plan and 19.23% are unsure if they have been given the option to discuss a plan. For question 10, only 75% of participants who receive medications from a nurse where they live feel the nursing schedule works well with their daily routine while 25% feel that the schedule does not work well with their daily routine. These findings suggest that it would be advantageous to participants for there to be more coordination and flexibility around scheduling of nursing visits. Focus group members unanimously agreed that the nursing schedule was an issue for many program participants.

As mentioned previously, another noteworthy finding from the quantitative portion of this survey was that not everyone at ServiceNet knew how to make a human rights complaint. Only 62.07% of participants felt informed about how to make a human rights complaint. Additionally, only 65.63% of participants felt that they would be heard if they were unsatisfied with their services. ServiceNet participants could benefit from increased opportunities to discuss self-advocacy and self-empowerment. Possible venues for increased opportunities could come in the form of further opportunities to connect with RLC peers and further informational opportunities provided by ServiceNet staff.

Other notable findings included quantitative responses related to employment and spirituality needs. Findings showed that there was a significantly low number of people who responded that their needs for employment and needs for religion were being adequately met by ServiceNet. The data reflected that 11.76% and 8.82% of participants respectively indicated that their needs employment and spirituality were being met.

Through this research process, these researchers determined that unmet religious needs are an area for further exploration in future surveys. As stated previously, it was unclear due to the format of this survey whether participants had religious needs that were not being met, if they unintentionally missed the question or if they did not define spirituality as an area they valued greatly or needed. In relation to employment needs, these researchers interpreted the results to mean that it would be helpful to have increased employment support services and for ServiceNet to re-examine the allotment of resources that would allow for these services and structures to be made accessible to participants.

Perhaps future research initiatives could explore what factors contributed to participant's perception that staff did not care. Another possible avenue for future researchers to take could be to gather data from staff, human rights officers, site managers, program directors, and family members of participants to learn more about their perceptions as well.

Implications of Qualitative Findings. In the qualitative data, there were notable highs in ratings of self-pathologizing and notably lows in ratings of self-compassion. Perhaps the reason for this was lack of information about ableism and internalized bias. Future research could look at how much training ServiceNet staff and participants have about ableism, bias, and actively anti-oppressive therapeutic frameworks.

Future researchers could directly ask quantitative questions related to self-pathologizing and self-compassion. Each of those questions should perhaps provide definitions for each term, since they were hard even for the researchers to conceptualize and find a consensus about the definitions. Another area for exploration in future research could try to determine whether there was a correlation between self-pathologizing, self-compassion and long term effects of medication and living with significant mental health challenges.

Summary. In this process, and with a limited scope of availability, these researchers uncovered a multitude of directions for continued research. For example, future researchers could also inquire about how long participants have been in the program, as this is likely to have had an effect on their responses, symptom severity, perception of their abilities/illness, and what recovery means to them. These research findings contained several important implications for future ServiceNet survey tools as well as lines of inquiry for future researchers. Although ServiceNet has come a long way in terms of meeting certain client identified needs, the agency still has a long way to go in terms of meeting other needs; this research illustrates certain ways in which ServiceNet as an organization could create change to better accommodate the self-identified needs of their participants and also ways in which participants may empower themselves.

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Appendix A:
Recovery Learning Community Focus Group Notes

Margot Reilly <mereilly@smith.edu>

Fwd: Notes from today's meeting
1 message

Caroline Evans <cwevans@smith.edu> Mon, May 23, 2016 at 1:35 PM
To: Margot Reilly <mereilly@smith.edu>

---------- Forwarded message ----------
From: [redacted]
Date: Tue, Jan 12, 2016 at 6:02 PM
Subject: Notes from today's meeting
To: Caroline Evans <cwevans@smith.edu>

Thanks Caroline! I think this is a fun and important kind of thing for us to do as a community even when the content is sometimes upsetting for folks. I'm glad we could support you in your project.

-Have you ever felt intimidated by ServiceNet staff?

-Do you feel like you have recourse if you are mistreated?

-What do you feel like you need in a therapist and do you feel like your therapist is a good match for you?

-Is there someone within ServiceNet who you think will advocate for your needs?

-Are you aware of your rights as ServiceNet client?

-What is the most important thing you think could change in this system?

-What else would you like us to know about your experience with us?

-Are you happy with your experience?

-Are all your needs getting met?

-How is the condition of your housing?

-Do you know who to call if there are problems?

-Do you feel like you have choice (or enough choice) regarding your treatment/medication?

-Do you feel like your choices are respected?

Give Incentive for taking Survey

-Is this helpful for you?

-Is this helping you achieve your personal goals?

-What else are you doing in your left that is helpful?

-What could ServiceNet do to help you meet your needs further?

-How much is ServiceNet helping you meet your goals?

-Have you had any experience completing a ServiceNet survey before?

-Do you think ServiceNet should have a 3rd party human rights office?

Food with survey

Making sure people understand the questions

Interview first choice

Collaborate

Appendix B:
Human Subjects Review Waiver Email

Fwd: NO HSR REVIEW REQUIRED
4 messages
Laura Wyman <lwyman@smith.edu> Fri, Feb 19, 2016 at 1:29 PM
To: Heather Crawford <hcrawfor@smith.edu>, Caroline Evans <cwevans@smith.edu>
See message from Elaine Kersten

---------- Forwarded message ----------
From: Elaine Kersten <tootieedward@verizon.net>
Date: Fri, Feb 19, 2016 at 1:08 PM
Subject: NO HSR REVIEW REQUIRED
To: mereilly@smith.edu, cevans@smith.edu, hcrawford@smith.edu
Cc: sdunn@servicenet.org, lwyman@smith.edu, mpruett@smith.edu, jlaterz@aol.com

Good afternoon, Margot, Heather and Caroline,

Thank you for your HSR application. Please be advised that we have determined that your project does not require HSR review. Our determination is based on the following:

1. The data collection defined in the application is part of ongoing program evaluation conducted by ServiceNet.

2. Your role is to analyze survey related data that will be de-identified prior to reaching you.

3. You will conduct and write up the analysis and work with a team to integrate the information into a report that will be used to reflect ‘how we are doing’ in terms of service recipients’ perspectives.

4. You will describe the evaluation and your specific role/function, along with your results, in your thesis report.

Please submit the attached form, checking item 2.2 (Seth Dunn is the person who has granted use of the data).

Be advised that you have been granted a waiver from HSR review for this project.

Thank you, and we wish you well in this most interesting project.

Elaine Kersten, EdD

Co-Chair, SSW HSR Committee

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Laura H. Wyman
Administrative Assistant/Research Sequence
Smith College School for Social Work
Lilly Hall
Northampton, MA 01063
(413) 585-7974
lwyman@smith.edu

Appendix C: ServiceNet Internship Approval Letter

servicenet
innovative mental health and human services

December 14, 2015

Heather Crawford
Margot Reilly
Caroline Evans
Smith College School for Social Work
Lilly Hall
Northampton, MA 01063

Dear Heather, Margot, and Caroline:

I am writing to confirm your acceptance as interns at ServiceNet for the purpose of developing and conducting program evaluation of our Hampshire Mental Health Recovery Services (MHRS). This project will involve collaborating with a small group of peers and persons served to develop a person-centered survey designed to reflect the values, interests, and needs of MHRS program participants. During early 2016 you will administer approximately 15 surveys to MHRS participants chosen at random. You will then analyze the result and write a final report which will be the foundation for your thesis requirement.

ServiceNet expects you to observe professional ethics and laws regarding confidentiality and respectful treatment of persons served. The agency does not operate an Institutional Review Board (IRB). However, any questions about confidentiality or human rights should be brought to my attention and the agency Human Rights Committee. We expect that you fulfil your requirement to submit a Human Subjects Review to Smith College.

On behalf of ServiceNet we greatly appreciate your interest and welcome your work with us.

Seth J Dunn

Seth J. Dunn LICSW
Director of Quality Management.

129 King Street • Northampton, MA 01060 • 413.585.1300
www.servicenet.org • fax 413.582.4252
a United Way partner agency

Appendix D:
Survey Instructions for Recovery Counselors

Participant Name:________________________ Team:__________________________

Dear Recovery Counselors,

Thank you very much for distributing these surveys! This research is being performed by three Smith College School for Social Work graduate school students working on a program evaluation project in collaboration with ServiceNet's peer mentors and Seth Dunn, ServiceNet's Director of Quality Management. Feedback helps us to improve our programs, so we ask for your help with the following:

1. Please distribute the sealed envelope to the participant in person as soon as you can. We understand that you are busy and we value the time you are taking out of your usual schedule in order to help us improve MHRS services, of which you are a vital part!
2. Ask the participant if they are willing to complete the survey and mail it back as soon as possible to Seth Dunn. We enclosed $2 to thank respondents in advance. Please mention that there is a stamped envelope inside in order to return the survey.
3. If the participant wishes to complete and return the survey immediately, please ask them to instead take a few minutes in private to complete it. Once they have taken the time to do so, they should seal the completed survey in the envelope and send it back. Please ask the participants to complete the survey thoughtfully.
4. Either mail it to Seth Dunn or return it directly to his box at 131 King St.
5. If the participant refuses to complete it, please return the unopened packet to Seth Dunn.

Again, thank you very much for your participation! We hope that the results of this survey come to benefit everyone at ServiceNet. If you have any questions or want more info, please contact Seth Dunn at 585-1361 or sdunn@servicenet.org.

Sincerely,

The Research Team:

Heather Crawford, MSW candidate, Caroline Evans, MSW candidate, Margot Reilly, MSW candidate, Seth Dunn, Director of Quality Management at ServiceNet, and the Peer Mentors at ServiceNet

Appendix E:
Letter to Survey Participants

February 29, 2016

Hello,

We are three Smith College Master's in Social Work students who are conducting a study about your experiences at ServiceNet. The purpose of this study is to find out if you are getting what you really need and want from ServiceNet. This is an opportunity for you to give your honest feedback about what you think and how you feel. Your answers will be completely anonymous and will help us understand your experiences.

The results of this study will be part of an ongoing conversation about what services provided by ServiceNet are helpful, what is not helpful, and what changes can be made to improve your experiences. We believe that real change does not happen unless everyone is involved in the process, and we very much value your opinions.

The information you provide will be used to write a report describing how helpful ServiceNet services are. The report will be available for anyone in the ServiceNet community. As a reminder, your name will never be included because the surveys are anonymous. We are enclosing $2 as a thank-you for your participation.

Please complete the survey as soon as possible. When you have completed it:

- Please put the survey back in the envelope
- Seal the envelope
- We prefer that you mail the completed survey. However, if that is not possible you may give it to your recovery counselor.

Thank you so much for taking the time to fill out the survey. Your honest answers are very much appreciated and will hopefully help you and other people get more of what you need.

Best,

Caroline Evans　　Heather Crawford　　Margot Reilly

Appendix F:
Program Experience Survey Tool

PROGRAM EXPERIENCE SURVEY

Please feel free to write additional feedback on the attached sheet of paper

Team:_________________________ Age: ☐21-29 ☐30-45 ☐46-60 ☐61 and older

Gender:_______________________ Race/Ethnicity: ____

1. Which of the following needs is ServiceNet MHRS/CBFS currently helping you with (check all that apply):

☐ emotional support
☐ housing
☐ voice in your treatment
☐ medication information
☐ personal growth
☐ recreation/fun
☐ spirituality/religion
☐ physical safety
☐ emotional safety
☐ transportation
☐ wellness
☐ legal support
☐ personal empowerment
☐ other: ______________
☐ independence
☐ social connection
☐ community resources
☐ educational
☐ finances
☐ employment
☐ none of the above

Please explain:____
____
____
____

2. Do you feel your Individual Action Plan (IAP) meets your vision of recovery?

☐ Yes ☐ No ☐ Unsure

Please explain:____
____
____
____

3. Does staff support your self-defined idea of recovery?

☐ Yes ☐ No ☐ Unsure

Please explain:____
____
____
____

4. Do you feel ServiceNet staff consistently pay attention to your needs?

☐ Yes ☐ No ☐ Unsure

Please explain:____
____
____
____

5. Do you feel you have enough information about your medications from your providers?

☐ Yes ☐ No ☐ Unsure ☐ Not applicable to me

Please explain:____

____

____

____

6. If you receive medication from a nurse who comes to where you live, please respond to this question. Does the nursing schedule work well with your daily schedule?

☐ Yes ☐ No ☐ Unsure ☐ Not applicable to me

Please explain:____

____

____

Turn over for side 2 questions

7. Do you feel you are treated like a human being?

☐ Yes ☐ No ☐ Unsure

Please explain:____

____

____

____

8. Do you feel that ServiceNet staff are available when you need to talk to them?

☐ Yes ☐ No ☐ Unsure

Please explain:____

____

____

____

9. Have you been given the option to discuss a plan to graduate from the program if you want to?

☐ Yes ☐ No ☐ Unsure ☐ Not applicable to me

Please explain:____

____

____

____

10. Do you feel that your opinions are respected by ServiceNet staff?

☐ Yes ☐ No ☐ Unsure

Please explain:____

____

____

____

11. Do you feel like you will be heard if you report that you are unsatisfied with your services?

☐ Yes ☐ No ☐ Unsure

Please
explain:____

12. Do you feel informed about how to make a human rights complaint?
☐ Yes ☐ No ☐ Unsure
Please
explain:____

13. Do you feel that staff care about you?
☐ Yes ☐ No ☐ Unsure
Please
explain:____

14. Do you feel that staff are trained well enough to meet your service needs?
☐ Yes ☐ No ☐ Unsure
Please
explain:____

Please feel free to write additional comments below:

Appendix G:
Focus Group one Researcher Script
INTRODUCTION:

Hi, my name is ___________ (and my name is ________) and we are Smith College master's students doing a research project to find out how well Servicenet is meeting the needs and goals of person's served as THEY define them.

Because this is a research discussion, I am using a script to make sure your ideas are the focus and my perspective doesn't influence the discussion. We only have until 7, and the first focus group is going to be open brainstorming.

You might be familiar with satisfaction surveys from the past. We're wondering if the responses were reflective of what MHRS participants really think about what they need and want, and about the services they get. We also wonder if the values, needs, and hopes of people are correctly understood. We would like to understand how well ServiceNet understands and is supporting person's served to meet THEIR OWN needs and goals. We are curious about these questions, and also would like to know what you want to be asked in a survey.

Based on information we gather from today, we will come up with a proposed survey, and then meet one more time to ask your feedback.

We have some guiding questions for the discussion, but first we are wondering if anyone has any questions about the project and why we're all here. (Open ended questions about what we have just said and what we're doing here.)

GUIDELINES: We want everyone to feel welcome and safe to be sincere in expressing your opinions. We have some ideas but we'd like to hear yours first.

- Privacy and confidentiality
- Personal details about traumatic experiences
- Respectful language

We have some specific areas that we'd like to explore with you, but if at any point you come up ideas that are different from these, we invite you to chime in and share them, even if it seems off-topic. We'd like this conversation to be collaborative.

FOCUSING THEMES:

Number of Questions:

1. What number of questions do you think would be most likely for participants to complete? We are concerned about survey fatigue and people not wanting to respond.

Types of Questions:

2. What do you feel about scale questions, the ones that ask "on a scale of 1-5"?
3. What do you think about open ended questions? (confirm knowledge of this)
4. What do you think about multiple choice questions?
5. What types of questions would participants be most likely to respond to? What combination and order of types of questions?

Response Rate: It's really common for the response rate to be low in surveys. We would like to design a survey that supports participation.

1. What else might help more people respond to the surveys?

Bigger Picture:

6. What do *you* want to know about how participants feel about the services at ServiceNet?
7. What questions should we be asking?

Speculative:

1. Although persons served have individual goals, what do you think might be some of the common and varied goals? Common and varied needs?

Personal Experience:

1. What has been your experience with completing surveys in the past at ServiceNet, or elsewhere?
2. What questions should we ask? Not ask? Why?

Logistics

1. Should the survey be distributed in paper?
2. by mail?
3. Given to persons served by ServiceNet staff? By us? By peers? By everyone?

Appendix H:

Focus Group One ServiceNet Peer Notes

12/15/15

Notes, Peer Focus Group to develop S.N. (ServiceNet) satisfaction survey developed with peer feedback:

Agree Short survey
1 page length with page to write comments on back

Scale Questions?
Multiple choice?
Open-ended?
Demographic?

Agree should be Anonymous- more honest information, with Team, Gender, and Age

A space to choose Yes or No answer and to explain.

Questions Brainstorm:

1. Do my services help me reach my hopes, dreams, desires in recovery/life?

Discussed learned helplessness:

2. Do you feel you have opportunities to grow, graduate from the program?
 True False

Why:

3. Do you feel you have incentive to move forward or not have reason to move forward?

Questions about IAP process and staff training to make it effective for participant.

4. Do you feel the IAP meets your vision of recovery?

5. Does staff meet your idea of recovery?

-and space to say more.

6. Does the nursing schedule support/interfere with your life activities?
-have a check box-some of the time
All of the time
None of the time

-or Yes/No/Unsure

Education about meds participants take and side effects:
7. Do you feel/wish you have enough info on your medications from the staff/nurses who give you meds?
-Yes/No
(No room for explanation, as people felt participants might tend to list their meds or be uncertain what to expand upon)

8. Do you feel consistently supported by staff in your goals?

9. Do you feel safe in your housing?

10. Do you feel supported by S.N. in gaining access to transportation to the places you need to get to?

Money management briefly discussed.

11. Do you feel you are heard, have a voice?

12. Do you have a space and time available to you on a consistent basis where your needs are met?

Staff communication briefly discussed.

13. Do you feel connected to the S.N. community?

14. Do you feel S.N. is meeting your needs to find human contact?

15. Has the staff identified resources in the greater community?

Professionalism at S.N. and how it feels to participants/too formal/too informal briefly discussed.

16. Do you feel you are treated like a human being?
-Yes/No Question
-Place to explain further.

17. Do you feel your physical and safety needs are met?

Snapping Question in middle to bring mindfulness back to the survey:

18. Do you feel like S.N. is helping you explore your hobbies?
19. Give us an example of something you accomplished?

Grp. Decides a question on fun would bring attention to the survey far better:
20. Does S.N. support you in having fun?
21. What's an example of something at S.N. that is fun?
22. Was there something in the past that was fun that you wish S.N. still did?
23. If you could add a S.N. service what would you add?

Next meeting:
-tweak language: respectful/trauma-informed
Meet at a different time so more participants might be able to attend

Discussed a raffle with a ticket in the survey mailed to participant that they bring in and match to one we keep. They have a chance at winning a gift card.

Appendix I:
Focus Group Two ServiceNet Script, Agenda and Survey Tool First Draft

INTRODUCTION:

Hi, my name is Margot Reilly and my name is Caroline Evans and we are Smith College master's students doing a research project to find out how well Servicenet is meeting the needs and goals of person's served as THEY define them.

Because this is a research discussion, I am using a script to make sure your ideas are the focus and my perspective doesn't influence the discussion. We only have until 7:15, and this second focus group is focused on consolidating information from our first group to select the final questions for survey. We hope to save the last 30 minutes to discuss how to best distribute the survey, as well as how to continue to collaborate once the data is collected.

Does anyone has any questions about the project and why we're all here?

We want everyone to feel welcome and safe to be sincere in expressing your opinions. Let's revisit the guidelines we made last focus group, and see if anyone would like to add anything.

AGENDA:

Big Picture Questions about the Survey:
- Do we still want to keep the length at 1 single-sided page? What about double-sided page?
- Discuss possibility of having a "needs meeting check-box".

Review each question and discuss (let's try to be as efficient as possible here)
- Are questions are clear, understandable, asking one thing at a time? Delete repeats?
- Discuss underlined questions-- could these be folded into needs meeting check box?

Vote on most important questions
- How do we want to "decide" things? Vote on each question? Each pick 20 and then tally for each? Is it going to be anonymous?

Overarching things to keep in mind after we've chosen the 15 questions:
- Is the language respectful and trauma informed? Culturally sensitive? Person-centered?
- How do you feel about formatting? Font size? Space between questions?

Concluding (final 20 minutes):

- How to get the best response rate with most honest answers?
    - How to deliver the survey? Is mailing going to get a good response rate? What about mailing out a $1 bill with the survey? What do we think about the raffle-- maybe we should keep it simpler? What about a survey online? Would that be accessible?Do we want to send a very short letter explaining why we're doing the survey and have all of us sign it?
- How does the focus group want to be involved after we acquire the data? One more time to discuss results and next steps/what to do with the data?
- What are we going to do with the data? Would you like us to have another meeting?

CLIENT SATISFACTION SURVEY

Do we want a statement about anonymity?

Team:______________________________ Gender:_____________________

Age:_________________

Is this too much identifying information that might compromise anonymity?
Why these identity factors and not others like Race, Religion, etc.?

1. Please identify which of the following needs ServiceNet IS currently helping you to meet (please check): **Do we like this idea? What other needs should we include? What should we prioritize-- should we eliminate anything?**

☐ emotional support
☐ medical care
☐ housing
☐ voice in your treatment
☐ medication information
☐ personal growth
☐ physical safety
☐ emotional safety
☐ transportation
☐ nutrition
☐ legal support
☐ recreation/fun
☐ independence
☐ social connection
☐ community connection
☐ educational
☐ other:_______________
☐ none of the above

Please explain:

2. Do my services help me reach my hopes~~, dreams, desires in recovery/~~ in life?

☐ Yes ☐ No ☐ **Maybe/unsure? Indifferent/Neither?**

Please Explain:

How many lines should these boxes be? (Please feel free to use back of survey?) If we format like this, we can only ask 10 questions total
Another space-saving alternative-- an open box at the end of the survey with a more open-ended question-- i.e. Please share what aspects of your services have been most helpful and unhelpful towards meeting your own needs and goals.
Do we think people will respond to each one? What are the pros and cons here?

3. Do you feel you have opportunities to ~~grow,~~ graduate from the program?
☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?
Please explain:

4. Do you feel you have incentive to move forward ~~or not have reason to move forward~~? **What do we mean by this? Is this question clear? How can we differentiate it from #3?**
☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?
Please explain:

5. Do you feel the Individual Action Plan (IAP) meets your vision of recovery?
☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?
Please explain:

5. Does staff meet your idea of recovery? **Does staff support your self-defined idea of recovery? How can we be more clear here?**
☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?
Please explain:

6. Does the nursing schedule support/interfere with your life activities? **How do we want to ask this-- it's asking two things at once?**
-have a check box-some of the time
All of the time
None of the time
Do we want to change the scale-- it might be confusing to the reader?
-or Yes/No/Unsure

7. Do you feel~~/wish~~ you have enough information ~~on~~ about your medications from the providers ~~staff/nurses~~ who give you medication?
☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?
Focus group participants decided here no room for explanation, as people felt participants might tend to list their meds or be uncertain what to expand upon. **Let's revisit this! What would be the drawbacks and benefits of having a box? Why would it be problematic if someone listed their meds? Does it send a message by not allowing a box?**

8. Do you feel consistently supported by staff to meet your goals?
☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

9\. Do you feel safe in your housing? **Should we make this question more general about housing, such as Are you satisfied with your housing? since safety gets addressed in another question?**

☐ Yes **☐ No** **☐ Maybe/unsure? Indifferent/Neither?**

Please explain:

10. Do you feel supported by S.N. in gaining access to needed transportation ~~to the places you need to get to~~?

☐ Yes **☐ No** **☐ Maybe/unsure? Indifferent/Neither?**

Please explain:

11\. Do you feel you ~~are heard,~~ have a voice **in your treatment plan? In how things operate at ServiceNet? Is your voice treated like it matters? Let's get specific!**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

12\. Do you have a space and time available to you on a consistent basis where your needs are met? **Do you have consistent time to get your needs met with staff? How can we make this more clear...**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

13\. Do you feel connected to the ServiceNet community?

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

14\. Do you feel ServiceNet is meeting your needs to find human contact? **Do you feel satisfied with ServiceNet's policies around physical contact with staff? Do we want to ask about this more directly? do we want this to be a separate question?**

☐ Yes **☐ No** **☐ Maybe/unsure? Indifferent/Neither?**

Please explain:

15. Has the staff identified resources in the greater community **that might be helpful to you?**

☐ **Yes** ☐ **No** ☐ **Maybe/unsure? Indifferent/Neither?**

Please explain:

16. Do you feel you are treated like a human being?

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

17. Do you feel your physical and safety needs are met? **These are two separate questions? Can we ask them separately, or is one more important to ask? physical safety v. emotional safety?**

☐ **Yes** ☐ **No** ☐ **Maybe/unsure? Indifferent/Neither?**

Please explain:

18. Do you feel like S.N. is helping you explore your hobbies?

☐ **Yes** ☐ **No** ☐ **Maybe/unsure? Indifferent/Neither?**

Please explain:

20. Does S.N. support you in having fun?

☐ **Yes** ☐ **No** ☐ **Maybe/unsure? Indifferent/Neither?**

Please explain:

DO WE WANT TO INCORPORATE THIS OPEN-ENDED QUESTIONS? Do we want to have a long box at the end?

19. Give us an example of something you accomplished?
21. What's an example of something at S.N. that is fun?
22. Was there something in the past that was fun that you wish S.N. still did?
23. If you could add a S.N. service what would you add?

__________The following questions were generated by RLC focus group____________

Have you ever felt intimidated by ServiceNet staff? **Is this a leading question?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Do you feel like you have recourse if you are mistreated? **Leading? Do you feel you will be heard if you are unsatisfied with services?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Is there someone within ServiceNet who you think will advocate for your needs?

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Are you aware of your rights as ServiceNet client? **Wording? Do you feel you're aware of your rights? Did staff inform you of your legal rights?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Are you happy with your experience? **Specify what kind of experience? Already covered by other questions?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Are all your needs getting met?

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Do you know who to call if there are problems? **if you have a problem with your services? if you have a problem in life in general?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Do you feel like you have choice (or enough choice) regarding your treatment/medication? **treatment OR medication-- can only count one at a time.**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Do you feel like your choices are respected? **Do you feel like you have choices?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Have you had any experience completing a ServiceNet survey before?

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

-Do you think ServiceNet should have 3rd party human rights officers? **Are you satisfied with how Servicenet deals with human rights issues?**

☐ Yes ☐ No ☐ Maybe/unsure? Indifferent/Neither?

Please explain:

Open-ended questions:

-What else are you doing in your life that is helpful?

-How much is ServiceNet helping you meet your goals?

-What do you feel like what you need in a therapist? Do you feel like your therapist is a good match for you?

-What is the most important thing you think could change in this system?

-What else would you like us to know about your experience with us?

What could ServiceNet do to help you meet your needs further?

Other question categories these researchers generated while compiling the survey:

- **Communication/language**
- **Staff training**
- **Do you feel that all ServiceNet participants are treated equally?**
- **Money management**
- **- does servicenet help you feel more hopeful about your future?**

- **Are you satisfied with ServiceNet's policies for conflict resolution between staff and clients**
- **Separate question about information about the structure, policies, and decision-making about how ServiceNet operates, and how much say participants get in these processes?**