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Sarah A. Hamilton

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CLIENTS’ EXPERIENCES OF RECOVERY-ORIENTED CARE FOR SCHIZOPHRENIA:
A QUALITATIVE RESEARCH STUDY

A Dissertation
Submitted to the McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Sarah A. Hamilton

December 2017
CLIENTS’ EXPERIENCES OF RECOVERY-ORIENTED CARE FOR SCHIZOPHRENIA:
A QUALITATIVE RESEARCH STUDY

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ABSTRACT

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December 2017

Dissertation supervised by Russell Walsh, Ph.D.

A recovery model of care has been widely accepted and instituted both in the U.S. and internationally, but research suggests that the model has not been employed uniformly. While existing research has focused on creating consensus regarding application of the model, the lived experience of those receiving the care has not yet been considered. In order to address this gap, the present study proposed a qualitative analysis of mental health consumers’ experiences of recovery-oriented care for schizophrenia. Potential participants were recruited through a Regional Mental Health Board and the author individually interviewed four participants in semi-structured interviews. A qualitative analysis was used to analyze the interviews. Themes were identified in individual narratives and were then compared across narratives to identify themes that were unique as well as points of convergence across participants. The results of the analysis supported the perception that implementation of recovery-oriented care had succeeded in
increasing the inclusion of mental health consumers in decision-making, but suggest that consumers still often feel disrespected or powerless and feel anxiety about potential abuses of power by providers. Additionally, the results confirm that consumers who are further along in their recovery have access to fewer supports than might be appropriate and that there are instances in which even providers and clients who are aware of the recovery model are not appropriately making use of the model’s tools. Implications for improving implementation of recovery-oriented care and directions for future research are explored.

*Keywords:* recovery-oriented care, recovery model, schizophrenia, qualitative research
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Introduction

Over the past several years, as the result of both my academic and professional experiences in the mental health field, I developed an interest in the growing move towards recovery-oriented care for individuals with schizophrenia. The recovery model of care recognizes the potential for stigma and oppression in diagnosis and treatment of mental illness. The model seeks to provide an alternative approach to treatment that attends to the consumer’s whole self. Recovery-oriented care has grown out of a need for greater attention to the well-being and rights of mental health consumers, buoyed by the work of mental health professionals who sought to view those with mental illness as a “whole person,” rather than focusing exclusively on their pathology. Deinstitutionalization, the mental health consumer/survivor movement, and a reassessment of the Kraepelinian model of schizophrenia contributed to the rise of the recovery model of care. This shift in approach has developed at different rates across the U.S. and, as a result, there has been a certain lack of consensus regarding method and application of recovery-oriented care. My own professional experiences suggest that, while many organizations embraced the theoretical position of recovery-oriented care, consistent implementation of such care provided a greater stumbling block.

Because of the growth of the recovery movement and the possibility for positive change in the mental health field’s approach to treating individuals with schizophrenia and other severe mental illness, I wanted to use my dissertation to further our understanding of recovery-oriented care. In recent years there has been significant research focused on creating consensus regarding the goals of recovery-oriented care. Additionally, research has sought to measure the degree to which recovery-oriented programs are meeting their own goals (Barrett et al, 2010; Bedregal, O’Connell, & Davidson, 2006; Borg et al, 2009; Marshall, Oades, & Crowe, 2009; O’Connell et
al, 2005; Piat & Lal, 2012). However, little to no research has addressed the actual experience of recovery-oriented care from the perspective of either mental health workers or consumers. This gap is an important one to fill as our mental health systems move forward in the implementation of recovery-oriented care. In order to address this gap, I proposed a small qualitative study using semi-structured interviews to explore mental health consumers’ experiences of recovery-oriented care.
Chapter One

Literature Review

Potentially Stigmatizing and Oppressive Aspects of Diagnosis and Treatment

The diagnosis of mental illness can serve as an important framework to aid communication, planning, and increase the patient’s understanding of their own process and experience (Yennari, 2011, p. 1). At its best, diagnostic terminology provides a common foundation in speaking about and treating mental illness, acting as a necessary bridge among providers, patients, and families. Whether or not they successfully address the need for a common foundation, diagnostic labels and the treatments that follow have the potential to be both stigmatizing and oppressive for the people who receive them.

The work of R.D. Laing (1959/1990; 1985), David L. Rosenhan (1973), and Erving Goffman (1961) was central in initiating a widely spread conversation about the stigma and oppression inherent in the psychiatric and psychological discourses and treatments. Goffman’s (1961) exploration of the social world of the hospital inmate sought to illuminate existence within a “total institution” and considered the effects of institutionalization on the “inmates” and staff (Capp, 2016, p. 105-106; Dyck, 2011, p.188). Laing and Rosenhan noted the ways in which the biomedical model of mental illness makes use of language that implies an inherent biological or environmental deficit in the patient. While this language is certainly an improvement on the moral or religious attributions of mental illness previously made in Western culture, it has the potential to diminish those with mental illness (Lester & Tritter, 2005; Yennari, 2011). This can lead to consumers feeling dehumanized by both their diagnoses and treatment (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001, p. 1621; Roe & Davidson, 2005, p. 93).

Although we have moved beyond explicitly connecting moral fiber with mental health,
deficit-centric discourses continue to locate the cause of mental illness within the individual, limiting the degree to which socio-cultural-political contexts and interpersonal relationships can be explored as contributing to the person’s well-being (Hare-Mustin & Marecek as cited in Cosgrove, 2005, p. 283). Diagnosis and treatment of mental illness can also impact the way in which the mental health consumer is viewed and treated by those around them. Consumers who have been diagnosed with a mental illness sometimes report feeling as though the diagnosis has changed them in the eyes of others. Friends, family, and employers tend to engage with them as a representative avatar of their diagnosis, rather than as a dynamic and complex person. After her diagnosis with schizophrenia at the age of 17, Deegan (1993) describes feeling as though everyone in her life began to view her every movement and word through the lens of schizophrenia, reducing her to merely an illness rather than viewing her as a whole person. The reduction of felt and perceived personal value that Deegan (1993) experienced following her diagnosis points to the unacknowledged but endemic discounting and devaluing of individuals with mental illness in Western culture.

Stier and Hinshaw (2007) argue that our current and past approaches to the diagnosis of mental illness and treatment of mental health consumers result in this unacknowledged stigma and discrimination, which effectively limits those individuals’ sense of agency and quality of life. As Deegan (1993) describes, the consumer often internalizes these explicit or implicit negative cultural perceptions, which influence the consumer’s own beliefs and behavior. Stier and Hinshaw (2007) state that as a result of both the external and internal stigma and discrimination, people with mental illness often experience:

(a) difficulties finding or keeping a job or living quarters . . . (b) restrictions on fundamental social rights (e.g., voting, having child custody, driving) . . . and (c) lack of
access to continuing treatment because of the current lack of parity in health care (p. 108).

These difficulties can act to significantly decrease the quality of life of mental health consumers. The stigma and discrimination from which these difficulties stem are embedded both in the systems that aim to treat and care for those with mental illness and our culture at large. Below, I will explore in more detail the nature of this stigma as well as the oppression experienced by individuals with mental illness.

**Stigma.** Stigma includes prejudice, discrimination, and stereotypes, as well as “attributing any and all negative attributes of the ‘outgroup’ member to his or her membership in the outgroup, fueling a vicious cycle of societal rebuff and personal internalization of the rejecting messages” (Stier & Hinshaw, 2007, p. 107). This attribution of negative characteristics is reflected in the experiences of Deegan (1993) and others who found that after being diagnosed with mental illness, their choices and behaviors were viewed and judged by others through the lens of their mental illness. This, in turn, had the effect of lessening Deegan’s (1993) own self-assuredness and limiting her own view of herself early on in her diagnosis and treatment.

Stigmatizing involves projecting onto an individual or group judgments as to what is inferior, repugnant, or disgraceful. It may thus translate disgust into the disgusting and fears into the fearful, first by singling out difference, next by calling it inferiority, and finally by blaming “victims” for their otherness (Porter as cited in Yennari, 2011, p. 1).

Although public awareness of mental illness and attempts to reduce stigma have increased in the past few decades, stigmatization of severe mental illness has also increased (Stier & Hinshaw, 2007). Stier and Hinshaw (2007) suggest that this may have something to do with the popularization of a biological/genetic explanation for mental illness: “a biological/genetic
explanation for mental illness yields a perception of less controllability but also greater stability (and even permanence), which appears, paradoxically, to lead to increased stigma” (p.109). So although the moral and personal burden has been lifted from mental health consumers, the lens of mental illness is never removed, rendering all of their behaviors and actions suspect.

In many ways, prejudice towards people with mental illness goes unnoticed. Stier and Hinshaw (2007) point out that “[u]se of derogatory language concerning such individuals is ubiquitous; for example, ‘retard,’ ‘psycho,’ and ‘crazy’ are common slurs across cultures that both children and adults often use offhand” (p. 107). Though there is a growing awareness of the implications in using words such as “retard” in a derogatory fashion, this does not seem to have happened for words that target those with mental illness (i.e., “psycho” and “crazy”). That these words are used so commonly and with so little reflection is indicative of how deeply stigma towards those with mental illness runs in our culture. Another example of this stigma is the fact that, despite relatively low rates of violence perpetrated by individuals with mental illness, there is a firmly entrenched cultural belief in the dangerousness of these individuals (Deegan, 1993; Flanagan & Davidson, 2009; Roe & Davidson, 2005). Popular media such as news reports, books, movies, and television predominantly depict individuals with mental illness in a negative (either dangerous or otherwise derogatory) light (Roe & Davidson, 2005; Stier & Hinshaw, 2007; Yennari, 2011).

As mentioned previously, these widely held cultural stigmas impact the day-to-day lives of people with mental illness, who routinely experience the effects of stigma in familial and social relationships, the quality of their medical and mental health care, and as a barrier to successful employment (Davidson et al, 2004; Flanagan & Davidson, 2009; Lester & Tritter, 2005; Stier & Hinshaw, 2007; Yennari, 2011). Lester and Tritter (2005) conducted discussion
groups made up of both consumers and a variety of healthcare and mental health providers in order to explore the difficulties and strategies of those with mental illness in managing their access to health care. When speaking about consumers, healthcare providers in the group expressed frustration at the stereotypical behavior of consumers inappropriately making use of health care services by either not showing up for scheduled appointments or showing up at times they were not scheduled (Lester & Tritter, 2005, p. 659). One of the consumer participants responded by describing the impact that a trip to a doctor’s office might have on her, exacerbating her anxiety to the point that she was unable to attend the appointment. Another participant responded that when she was reaching out for help from a doctor, she was not doing so on a whim, but that it was always in times of extreme need (Lester & Tritter, 2005, p. 660).

Gray (2009), discussing his own experience in hospitalization, also talks about the delicate balancing act that clients must sustain in reaching out for help from providers. One must be doing poorly enough that they will be taken seriously, without being in such a place of suffering that communication becomes difficult.

As Stier and Hinshaw (2007) suggest, another area of great difficulty for people with mental illness is in navigating stigma as it regards finding and keeping employment. Participants in Lester and Tritter’s (2005) study spoke about the way in which others suggest they are now (since their diagnosis) less capable than they were previously,

He said that realistically he thought I should think about taking on a bit of voluntary work, but nothing too stressful, and not to even think about going back to the job that I’d trained at university for, as a social worker. He suggested that I should basically try and get a job packing boxes for the rest of my career (p. 661).

As discussed previously, this external diminishing of one’s value can easily become internalized,
resulting in decreased self-perceptions of ability and agency. Another participant in Lester and Titter’s (2005) study spoke about this shift from certainty about their abilities and value to uncertainty:

“There’s [sic] lots of things I used to be able to do.” “I used to do a lot of drawing and painting,” I said, “I can’t even pick up a pencil now”, I said, “I’ve just forgot how to draw and paint . . . I used to operate power tools. I used to run a gang of 50 men on building sites, all over the world. But whether I could do it now, I couldn’t tell you” (Lester & Titter, 2005, p. 661).

The internalized narratives of hopelessness and incompetence can work against any previous life successes, diminishing an individual’s certainty in their pre-existing abilities. In addition, mental health consumers may feel discouraged from pursuing new opportunities once others are lost. In this way, the stigma and prejudice of others becomes a self-fulfilling prophecy that can keep the consumer from reaching out and striving in new directions.

**Oppression.** Along with the personal effects of stigma regarding mental illness that consumers may have to contend with, diagnostic labels may carry an additional burden of oppression. “[P]sychiatric labels create certain realities and marginalize others and in the process may inadvertently sustain unjust social relations . . . such labeling may reinforce gender, class, and race bias” (Cosgrove, 2005, p. 284). Although psychiatric diagnosis has undoubtedly come a long way, de-pathologizing homosexuality for example, it is also certain that there are other, subtler forms of oppression which psychiatric diagnosis still reifies. For instance, research suggests that diagnostic labels such as schizophrenia are applied disproportionally to African-Americans and that, in comparison to Caucasians, African-Americans are more likely to be hospitalized against their will (Fernando, 2010; Whitaker, 2010, p. 165, 173). Socioeconomic
status also seems to affect the diagnosis of schizophrenia, with those in the bottom quartile being eight times more likely to be diagnosed as schizophrenic than those in the top quartile (Whitaker, 2010, p. 173). Quality of treatment is often also determined by the financial and social supports available to an individual, dictating their quality of life as well as their quality of care.

It is clear, however, that the oppression experienced as a result of diagnosis cuts across race and socioeconomic status as well. Gray is a doctor and an academic in the mental health field who was diagnosed with schizophrenia as an adult. He writes about his experience of being kept in a psychiatric hospital and required to take antipsychotic medications against his wishes for 12 months:

My strange religious beliefs were perhaps quite rightly classified as delusions and discounted by my psychiatrist, nurses, and also my family, but this left me with the impression that my experiences, however negative and painful, were also being discounted and that I was not being listened to in order to be more deeply and humanely understood (Gray, 2009, p. 661).

The dismissal and discounting of his experience made Gray feel dehumanized and ignored by those around him, as though he had nothing to contribute to the process of moving out of psychosis. Gray (2009) recounts the generally accepted wisdom among the patients in the hospital:

Never admit that you hear voices; certainly never answer them; do exactly as you are told by staff or concerned family or you will be seen as ill; never question your diagnosis or disagree with your psychiatrist; and be compliant and admit your mental illness or you will never be discharged (p. 661).

Once again, the contributions of the client are seen as suspect, colored by their diagnosis. The
individual’s agency and free will are bracketed, at the very least temporarily. All interactions with people of power (doctors, nurses, etc.) are fraught with fear because of the way in which any and all behavior that is deemed suspect can be used as proof against the sanity of the client (Gray, 2009, p. 662).

The mental health consumer in treatment is not just robbed of agency and respect; they are sometimes also oppressed by the approach and method of treatment. Lester and Tritter (2005) reported that:

> [b]oth the effects of the mental illness and pharmacological treatments were described by most users as imposing restrictions on their ability to live their lives, and were therefore, in some sense, oppressive . . . The side effects of medication . . . made worse by the relative lack of discussion and information from health professionals (p. 658).

Patients are often put in positions of powerlessness, prescribed medications without knowing what specifically the medication will target and what the possible side effects are. Patients feel that their complaints about side effects are often minimized or ignored (Lester & Tritter, 2005, p. 658). When it comes to addressing instances of compulsory treatment, patient and staff members’ attitudes often diverge, with patients feeling that their rights are more important than treatment and the staff feeling the reverse (Roe & Davidson, 2005, p. 91). Lester and Tritter (2005) argue that, “[t]he potential for compulsory detention and for medical treatment administered without consent within the community are constraints on legal and civil rights” (p. 665). Although such treatments are undoubtedly most often administered out of genuine concern for the patient’s well being, many argue that it remains an infringement on an individual’s rights. When in hospital, violence is sometimes used as a tool for getting noncompliant patients to take their medication, usually via depot injection. This violence is often
conceived of as right, as just, and in the patient’s best interest . . . Violence as care is an oxymoron and hides the institutionalized abuse of people with schizophrenia and mental health problems (Gray, 2009, p. 662).

Mandating the use of medication is less of a burden, in terms of finances and manpower, than focusing on alternative treatments that are less physically impactful on patients, but this supports ease for the professional over wellbeing of the patient (Gray, 2009, p. 662).

**Approaches to Mental Health Care in the Recovery Movement**

The recovery movement can be seen, in many ways, as an answer to the stigma and oppression outlined above. Although its roots begin much earlier, the recovery model’s predecessors truly gathered steam in the 1960s and 1970s. R.D. Laing and others in the “anti-psychiatry” movement began to question the way in which biological psychiatry engaged with patients, suggesting instead that social phenomenology be used in attempting to understand the individual patient in their social and familial context (Laing, 1959/1990; Yennari, 2011). Laing and those that followed him developed therapeutic communities, which operated without labeling, medication, or involuntary treatments, but few of these communities functioned in the long term, often degenerating due to internal conflict, a lack of funding, or conflict with the communities in which they existed (Yennari, 2011).

The Soteria Project, led by Loren Mosher, was initially founded in order to assess whether “treating acutely psychotic people in a humanistic way, one that emphasized empathy and caring and avoided the use of neuroleptics, [would] be as effective as the drug treatment provided in hospitals” (Whitaker, 2002/2010, p. 220). Soteria would provide a safe place for those in acute psychosis to stay through their crisis. Rather than staffing it with mental health workers, Mosher staffed Soteria with:
People who had evident empathy for others, along with the social skills to cope with people who could be strange, annoying, and threatening. “I thought that sincere human involvement and understanding were critical to healing interactions,” he recalled. “The idea was to treat people as people, as human beings, with dignity and respect” (Whitaker, 2002/2010, p. 220-221).

The Soteria House opened in Santa Clara, California in 1971. There was room for six initial residents, all acutely ill, made up entirely of clients with poor projected outcomes. The mandate of staff in the face of such psychosis was to “‘be with them.’ That meant listening to their crazy stories, which often did reveal deeper stories of past trauma – difficult family relationships, abuse, and extreme social failure” (Whitaker, 2002/2010, p. 221). Residents were expected to help with household chores and hold to a mutually agreed upon code of behavior. Some structured activities were offered, including yoga, reading, and massage. The outcomes were striking.

At six weeks, psychotic symptoms had abated in the Soteria patients to the same degree as in medicated patients. Even more striking, the Soteria patients were staying well longer. Relapse rates were lower for the Soteria group at both one-year and two-year follow-ups. The Soteria patients were also functioning better socially – better able to hold jobs and attend school (Whitaker, 2002/2010, p. 222).

Unfortunately, Soteria faltered and eventually failed due to a lack of funding and unbelievably strong opposition within the broader psychiatric community.

In 1981 in Boulder, Colorado, psychiatrist and psychoanalyst Edward Podvoll developed the Windhorse Project. Hoping to find a way to keep individuals with psychosis in a home environment rather than a hospital environment, Podvoll created “therapeutic households” that
would be tailored to the needs of the client. These were households in which patients who had moved out of the most acute phase of their psychosis would leave the hospital and live with one or two other roommates who had been specifically chosen for the position. The responsibility of the roommate lay in working with the patient to create a healing, shared home environment. A team of eight people, managed by a team leader, was created for each patient. Podvoll (1990/2003) described the approach used in the creation of the healing, shared home environment:

The shift therapists are attending to the entire household as much as they are to the patient . . . they also maintain a larger awareness of a person’s entire environment. They attend to the patient’s living space and to the people who live there, and even to the patients’ friends and family (p. 252).

Decisions about who would be on the team were sometimes dictated by medical need but were more often based on the personal interests and needs of the patient. In this way, team members might be chosen for their skill as musicians, writers, or for the nature of their personal presence. A schedule was drawn up in which each team member would spend about 3 hours a week with the patient. Podvoll (1990/2003) described the purpose and benefit of the arrangement:

The process of recovery in general, and from psychosis in particular, depends on creating an atmosphere of simplicity, warmth, and dignity. When the team therapists together perform the actions needed to establish the kind of environment and tone, recovery begins to happen; *islands of clarity* begin to gather and flourish [italics in text] (Podvoll, 1990/2003, p. 253).

In order to encourage these “islands of clarity,” a healing environment was created around the patient. This included the entire household (patient and family/roommates) beginning a
macrobiotic cleansing diet, getting physical exercise, taking all medications as prescribed, attending to the cleanliness of the environment and the body, and an open and receptive environment that is conducive to discussion. When it was the desire of the patient, medication reduction would become a shared goal that was closely monitored. In 1989, Friendship House, a joint venture between the Boulder County Mental Health Center and Naropa University based on the Windhorse model, opened to accommodate 6 patients with chronic psychosis. Friendship House and the Windhorse Project are still in operation today (Podvoll, 1990/2003).

In addition to these instances of care that challenged the accepted norms for mental health consumers, research began to suggest that the previously assumed deteriorating trajectory of psychosis was not universally accurate (Anthony, 2000; Davidson & Roe, 2007, p. 462; Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008, p. 5; Harrow & Jobe, 2007, p. 406). Results from research such as the WHO studies on schizophrenia and the ISoS studies suggested that schizophrenia was a:

[m]ultidimensional disorder with both an unpredictable course and a far from certain outcome . . . declines or improvements in one area of functioning . . . did not predict similar changes in other areas of functioning . . . with each domain being relatively distinct and independent (Davidson, 2003, p. 11).

These findings were in stark contrast with the Kraepelinian model, upon which an understanding of the trajectory of schizophrenia had depended for the previous 100 years (Hopper & Wanderling, 2000). While studies suggest that about 20-65% of patients will have a remission from symptoms of schizophrenia, the issue remains of how to restructure treatment for those whose symptoms do not remit (Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008, p. 7).

A crucial part of re-thinking treatment approach has been differentiating between the idea
of “recovery from” schizophrenia and “recovery in” schizophrenia. The research mentioned above mostly refers to “recovery from,” which suggests an “amelioration of symptoms and other deficits associated with the disorder to a sufficient degree that they no longer interfere with daily functioning” (Davidson & Roe, 2007, 460). “Recovery in” schizophrenia, on the other hand, refers to the individual’s efforts to overcome the effects of being a mental health consumer and an improvement in quality of life to some degree, whether or not symptoms are still present. Acceptance that “recovery from” is possible has gained ground, while “recovery in” has become the focus of efforts to shift and improve care for those with schizophrenia (Davidson, O’Connell, Tondora, Styron, & Kangas, 2006, p. 641; Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2007, p. 7; Le Boutillier et al, 2011, p. 1470). Davidson and Roe (2007) note that although the recovery movement began as a civil rights movement:

[t]his emphasis is quickly overshadowed in clinical settings where the focus gravitates initially to disorder, deficit, and disability . . . But from the perspective of the person with the psychiatric disability, focusing solely on deficit and pathology is not only overly narrow and limited in its utility, but misses the very point of the civil rights argument . . . Recovery refers to the rights to access and join in those elements of community life the person chooses, and to be in control of his or her own life and destiny, even and especially while remaining disabled [italics in text] (p. 465-466).

Here, Davidson and Roe (2007) stress that the shift proposed by “recovery in” has less to do with concrete changes in diagnosis and symptoms and much more to do with acknowledging the consumer’s right to be an agentic director of their own lives, whether or not they ever become symptom free.

The push towards recognizing the civil rights of those with mental illness was initiated by
the Mental Health Consumer/Survivor Movement, whose self-advocates are made up of individuals who have been on the receiving end of mental health care. These self-advocates work to change the conditions that are encountered in mental health care, based on the shared conviction that “[people with psychiatric disorders] do not need other people to make decisions or to speak on their behalf; that, despite their disabilities, they are capable of doing so for themselves” (Davidson, 2003, p. 38). For the past 25 years, the Mental Health Consumer/Survivor Movement has fought for the “recovery” model as an alternative to the Kraepelinian model that previously predominated psychiatric care. Davidson (2003) describes this recovery model:

At its most basic level, the recovery model argues that psychiatric disability is only one aspect of the whole person . . . and that recovery from psychiatric disorder does not require remission of symptoms or other deficits . . . What recovery seems to entail is that people overcome the effects of being a mental patient – including rejection from society, poverty, substandard housing, social isolation, unemployment, loss of valued social roles and identity, and loss of sense of self and purpose in life – in order to retain, or resume, some degree of control over their own lives (p. 38).

Beginning in the 1990s, the broad vision of recovery has become more widely accepted and has, in fact, become the stated theoretical approach of a number of institutions, states, and countries (Anthony, 2000, p. 160; Davidson, O’Connell, Tondora, Styron, & Kangas, 2006, p. 640; Davidson & Roe, 2007, p. 460; Marshall, Oades, & Crowe, 2009, p. 654; Piat & Lal, 2012, p. 289)

**The 10 goals of the recovery movement.** While there is widespread agreement on the benefit of the recovery model, there has been little cohesive work on universalizing the
application and implementation of the recovery model (Anthony, 2000; Bedregal, O’Connell, & Davidson, 2006, p. 96; Borg, 2007, p. 1; Borg, Karlsson, Tondora, & Davidson, 2009, p. 84; Davidson, O’Connell, Tondora, Styron, & Kangas, 2006, p. 640; Davidson & Roe, 2007, p. 460; Le Boutillier et al, 2011, p. 1470; O’Connell, Tondora, Croog, Evans, & Davidson, 2005, p. 379). One of the stumbling blocks in application and implementation of the model in any generalizable way is that it is, at least theoretically, understood “as a process, not an outcome” (Frese & Davis, 1997, p. 244). This aspect of the recovery model has been in some ways glossed over in its acceptance at the levels of policy and service development. Recovery has been repeatedly described as representing:

[n]ot a cure-like end-point, but a state of being and becoming, a path rather than a destination. The course of that path is understood to be highly singular or unique; no two people will have identical paths or use the same benchmarks to measure their journeys (Jacobson & Curtis, 2000, p. 334).

Our medicalized and manualized approach to mental health treatment may not be readily amenable to this fluid understanding of recovery. What the field does seem to have achieved is a set of ten goals which recovery-oriented care should aim to address. These goals are the combined work of Anthony (2000), Borg, Karlsson, Tondora, and Davidson (2009), Davidson et al (2007), Roe and Davidson (2007), Davidson, Schmutte, Dinzeo, and Andres-Hyman (2008), and Le Boutillier et al (2011). In the following, I will outline these agreed upon goals.

1. **Being supported by others.** This goal speaks to the need to incorporate important others into the recovery process. At best, recovery is conceptualized as a socially supported effort. Becoming interdependent in one’s community and having supportive others and role models, whether they be family members or friends, professionals, community members, or
peers has been repeatedly shown to have a positive impact on quality of life. Unfortunately, many mental health consumers experience a major loss of social supports outside of their care settings.

2. **Renewing hope and commitment.** Having a sense of hope and believing in the possibility of a renewed sense of self and purpose, accompanied by desire and motivation, is essential to recovery. This sense of hope may be derived spiritually and/or from others who believe in the potential of a person, even when he/she cannot believe in him/herself. This is one of the many areas in which supportive others play an important role. This goal aims to combat the internalized self-stigma and loss of value that many individuals experience, as described previously.

3. **Engaging in meaningful activities.** Expanding and occupying normal, functional social roles, and making worthwhile contributions to a community of one’s choice is another essential aspect of recovery. Mental health consumers speaking about their success in recovery frequently refer to the importance of feeling as though they contribute in some meaningful way and are able to give back to those around them, rather than feeling as though they have nothing to offer in return.

4. **Redefining self.** This goal aims at re-conceptualizing mental illness as simply one aspect of a multi-dimensional identity, rather than the client assuming the role of “mental health consumer” as their primary social role. This entails a shift in focus that takes stock of individual strengths and traits to create a fuller sense of personhood and encourages the consumer to continue pursuing skills and interests as they might without having received a diagnosis.

5. **Incorporating illness.** This goal aims to assist the mental health consumer in acknowledging and accepting the limitations imposed by one’s illness, while learning what
and steps one has to take in order to continue living their lives to the fullest while living with mental illness.

6. **Overcoming stigma.** People must recover from the social consequences and societal stigma associated with illness as well as from the effects of the illness itself. Recovery involves developing resilience to stigma and/or actively fighting against it. Learning to live with and finding ways of overcoming barriers including, but not limited to, those posed by the illness itself.

7. **Assuming control.** This goal aims at making the client the primary leader in treatment planning. It is believed that assuming control over one’s life and rehabilitation contributes to the redefined sense of self as an active, effective agent. Opportunities must be available for individuals to make choices, and they must also be afforded opportunities to take risks, to fail, and to learn from their own mistakes as well as from their successes.

8. **Managing symptoms.** The mental health consumer must learn what they need to do in order to best manage their symptoms, not just in terms of medication, but also with any other managing technique that the individual finds useful. Although complete symptom remission is not necessary, being able to manage symptoms in some way is a part of recovery. This involves periods of good and difficult times, setbacks and accomplishments, and times when symptoms may be more or less controlled. There is a shift in emphasis from simply receiving services to actively participating in and using treatments of one’s own choice in order to bring symptoms under a degree of control.

9. **Becoming empowered and exercising citizenship.** The mental health consumer has the right to exercise their civil rights in all areas, such as employment, living circumstances, and romantic relationships. At the same time, the individual has the right to take on the same
responsibilities (e.g., paying taxes, voting, volunteering) as other citizens.

10. Promoting access. This goal aims to improve and encourage mental health consumers’ access to integrated community settings such as clubs, places of worship, and employment opportunities. Many individuals with mental illness are offered only opportunities that are specifically designed for those with a disability of some kind. For instance, their treatment team might help them look for work but only locate opportunities that are seen as “low stress,” as described in Lester and Titter’s (2005) research. They may only be provided with opportunities to socialize with others with mental illness, etc. By encouraging access to integrated community settings, the consumer is able to build relationships and experiences that extend beyond the world of mental health care and support.

Recovery-Oriented Care in Practice

Despite the above-stated goals, and a shift in tone and stated mission throughout much of the mental health field, it seems as though individuals with serious mental illness continue to be met with inflexible and paternalistic modes of care as well as dehumanizing interactions with those responsible for their care (Borg, Karlsson, Tondora, & Davidson, 2009, p. 84). “Although key building blocks for recovery-oriented practice have been proposed in international policy, research literature, and first-person narratives, it is a nebulous concept that is understood in a number of ways and is difficult to apply” (Le Boutillier et al, 2011, p. 1470). The widespread agreement on the need to apply recovery-oriented care has not, unfortunately, led to consensus about what such care would look like or how to implement it.

Borg, Karlsson, Tondora, and Davidson (2009) considered the gap that remains between the “humanistic and holistic sounding vision statements” and “the lack of concrete procedures or treatment approaches that embody these values” (p. 84). The authors point to person-centered
care planning in Connecticut and Open Dialogue treatment in Finland as examples of care that have bridged the gap between rhetoric and action. In the person-centered care-planning model, a facilitator uses a core set of questions to create a more nuanced and holistic image of the client. These facilitators are trained in motivational intervention techniques, active and empathic listening skills, community-based asset mapping and advocacy, as well as the development of psychiatric advance directives (Borg et al, 2009, p. 87). Participants in a randomized control study reported increases in their experience of mental health care as beneficial, and a greater awareness of the positive role that employment, spirituality, social connection, and recreation played in their treatment when person-centered care planning was used. This resulted in an increased sense of control and agency, although it was accompanied by a decreased sense of satisfaction in their inability to find employment, possibly pointing to an area in which greater support is needed (Borg et al, 2009, p. 87-88).

Open Dialogue was developed in the 1980s in Lapland in conjunction with the Turku project and the Finnish National Schizophrenia Project. Open Dialogue is centered on three principles of communication: tolerance of uncertainty, polyphony in social network, and continuity of care (Alanen, Lehtinen, Rakkolainen, & Aaltonen, 1991, p. 365-366; Borg et al, 2009, p. 88). Central to the tenets of Open Dialogue is the involvement of the consumer’s extended network, as well as the Windhorse-like approach of offering support in the individual’s home. Because of the unique involvement of the social network, one of the primary aspects of Open Dialogue involves facilitating communication between those involved (Alanen, Lehtinen, Rakkolainen, & Aaltonen, 1991, p. 365-366; Borg et al, 2009, p. 88). Practitioners are trained to keep dialogue open until the participants create a mutually agreed upon solution, rather than stepping in to dictate the solution. Follow-up studies on the use of Open Dialogue have shown
that in first episode psychosis, within five years 82% of participants had no residual psychotic symptoms and 86% had returned to their studies or to full time work. Only 19% relapsed during the next three years and only 29% had used neuroleptic medication at some point in treatment. One of the most important aspects seemed to be the meeting with client and social network as soon as possible after the onset of symptoms (Alanen, Lehtinen, Rakkolainen, & Aaltonen, 1991, p. 365-366; Borg et al, 2009, p. 88)

Another example of the care being offered as part of the Turku Project is termed need-adapted treatment. The development of this treatment stems from an understanding of the heterogeneous nature of schizophrenia, underscoring the importance of the individual’s developmental history and context. Pharmacotherapy factors into need-adapted treatment as well, but requires that the patient understand the purpose of the medication they’ve been prescribed. The dose and length of time medication is taken tends to be notably shorter than in other approaches to treatment for schizophrenia (Alanen, Lehtinen, Rakkolainen, & Aaltonen, 1991).

Based on these examples, Borg et al (2009) suggest that the three most critical steps in bridging the gap between rhetoric and practice are: “1) reorientation from patient to personhood; 2) reorientation of valued knowledge and expertise; and 3) partnership and negotiations in decision-making” (p. 90). While it remains uncertain how the individual practitioner or even an organization might put these steps to use without widespread change, Borg et al (2009) have fostered a dialogue that recognizes gaps in current approaches to care and suggests that shifts must be made in implementing the recovery model.

Despite these findings and the development of such successful care models, Borg et al (2009) suggest that:

[a]lthough the empowerment of service users and the need for partnerships between users
and practitioners have been prominent themes in mental health policy in most Western countries for the past decade . . . there remains a gap between this rhetoric and what continues to be happening in the field (p. 84).

Some authors have stepped in to try and address this gap by assessing mental health providers’ knowledge of recovery-oriented practices and their experiences in attempting to implement these practices.

Bedregal, O’Connell, and Davidson (2006) used the Recovery Knowledge Inventory (RKI) to measure mental health providers’ knowledge and attitudes about recovery. Participants were 144 mental health providers from nine different agencies in Connecticut. The authors found that the participants did best on the third component of the RKI, *The roles of self-definition and peers in recovery*, “indicating that providers appreciated the need for the person in recovery to develop a positive identity” (p. 101). The next highest scores were on the first component, *Roles and responsibilities in recovery*, indicating that participants had a good understanding of the need for both provider and patient to take active roles in the recovery process. The third highest scores were on component four, *Expectations regarding recovery*, “suggesting that staff have less knowledge of how to develop realistic yet hopeful expectations of their clients” (p. 101). Participants’ lowest scores were on component two, *Non-linearity of the recovery process*, which indicated participants’ lack of understanding regarding the complex nature and the diverse range of experiences which can make-up the recovery process.

Piat and Lal (2012) conducted focus group interviews with service providers of recovery-oriented care in Canada. Their aim was to “elicit providers’ experiences and perspectives on recovery-oriented changes within their organizations and the barriers they faced in implementing recovery-oriented practice” (p. 290). Participants were 68 mental health service providers from
three agencies. The authors found a range of opinions being expressed by the participants, which were broken down into three overarching themes: 1) Expressing positive attitudes towards recovery-oriented reform, 2) Expressing skepticism towards recovery-oriented reform, and 3) Experiencing challenges with the implementation of recovery-oriented practice. For the purposes of my discussion, the responses to the first and second theme are the most salient. Responses in the first theme represented providers’ perceptions of recovery-oriented care:

[a] radical change in the mental health care system and a better way of delivering services . . . the concept of recovery provides a unifying foundation upon which different stakeholders in the community can work together . . . recovery-oriented reform entailed shifts within the power relationship between service providers and consumers (p. 292).

Responses in the second theme suggested that some providers felt that:

[r]ecovery-oriented reforms . . . did not contribute anything new to their practice. They . . . were already implementing recovery long before it became a politicized concept. They characterized the term recovery as a “buzz word” or “fad” in mental health discourse, and a re-invention of what already existed . . . Additionally, [they] questioned whether recovery-oriented reforms . . . will have an ultimate impact on client outcomes (p. 292).

Results from Bedregal, O’Connell, and Davidson’s (2006) and Piat and Lal’s (2012) studies suggest that, overall, mental health providers support the ideas and shifts that recovery-oriented care proposes. However, both studies suggest that there is some disconnect between an appreciation of the theory and an understanding of how to apply the ideas in practice, particularly when it comes to shifting providers’ attitudes and expectations with regard to their clients’ actions.

With regard to the consumer’s experience of the implementation and success of recovery-
oriented care, Marshall, Oades, and Crowe (2009) sought to gauge consumers’ perceptions of recovery-oriented case management, specifically the Collaborative Recovery Model (CRM) of case management. The authors used a self-report questionnaire to assess perceptions of the usefulness of the guiding principles and components of the CRM approach, which include responsibility, collaboration, autonomy, motivation, needs-assessment, goal setting, and homework. Participants were 92 consumers (47 male, 30 female, 15 not identified), mostly middle-aged, primarily diagnosed with schizophrenia (68%). Participants reported being able to identify significant differences with the recovery-oriented case management, in particular with regards to being encouraged to take responsibility for their own recovery, collaboration with case managers, and “homework” activities.

Barrett et al (2010) conducted a study in order to assess the connections between recovery-oriented treatment, “subjective experiences of consumer empowerment,” and satisfaction with mental health care (p. 153-154). The participants were a sample of 45 clients from two different programs. The participants were predominately male, Caucasian, middle-aged, and unemployed. The authors used the Recovery Self Assessment (RSA) instrument, the Making Decisions Empowerment Scale (MDES), and the Mental Health Statistics Improvement Program, Consumer Survey, Adult Version (MHSIP-CS). The authors found that recovery-oriented treatment was a significant predictor of participant satisfaction with treatment and feelings of empowerment.

O’Connell et al (2005) conducted a much broader evaluation of the recovery-oriented model as used in Connecticut. The authors used the Recovery Self Assessment (RSA) tool to “assess the degree to which recovery-oriented practices were perceived to be implemented” in the agencies studied (p. 379). The RSA is made up of 36 items organized according to five
factors – Factor 1) *Life Goals*, Factor 2) *Involvement*, Factor 3) *Diversity of Treatment Options*, Factor 4) *Choice*, and Factor 5) *Individually-Tailored Services*. Participants were 974 individuals (68 directors, 344 providers, 326 consumers, and 229 family members/significant others/advocates) from 82 agencies in Connecticut. The study is particularly interesting in that it gives us some idea of the variance in responses from the different groups of participants. For instance, providers gave significantly lower ratings overall than did consumers. In general, there was agreement across groups that the agencies were providing services consistent with recovery-oriented care. Agencies were rated highest on items related to goal setting and supporting consumers in pursuing personal interests. The agencies were rated lowest on involving consumers in service design, management, and provision.

While all of these studies hint at some exciting successes with regards to the implementation of recovery-oriented care as experienced by both mental health providers and consumers, all except for Piat and Lal (2012) relied on surveys or other assessment tools for participant feedback. Although Piat and Lal (2012) have conducted some important initial work on the perspectives of mental health providers towards recovery-oriented care, there are still major gaps in the research when it comes to understanding the lived experiences of both mental health providers and consumers when it comes to the actual application of recovery-oriented care. Given the dearth of qualitative research on the lived experience of consumers and providers in recovery-oriented care, there seems to be a significant need for research that addresses the experience of consumers diagnosed with schizophrenia in recovery-oriented care in order to further the ongoing dialogue surrounding the implementation and benefits of the model.

To address this gap, I proposed conducting semi-structured interviews with both mental health care workers and clients diagnosed with schizophrenia regarding their experiences of
recovery-oriented care in comparison to previous types of care in which they have worked or been treated. I believe that in order to more fully understand the process of recovery-oriented care and move forward in its successful implementation, it is important to gain a greater understanding of where the field currently stands.
Chapter Two

Research Method

Participants

I had initially proposed recruiting mental health providers currently employed at recovery-oriented programs and mental health consumers currently receiving care in a recovery-oriented program. My intention was to recruit providers and consumers who had been involved in mental health care for at least fifteen years, from the same program. As will be discussed below, no mental health providers responded to my recruitment efforts.

Participants for this study met the following criteria: they were mental health consumers who had at some point been diagnosed with schizophrenia, were currently receiving some kind of mental health services, had been receiving mental health services for at least fifteen years, and did not currently have conservators of person. Diagnosis of schizophrenia was based on self-report. Participants were not targeted by gender, sex, ethnicity, or race due to the difficulty of finding participants who fit the more general criteria required for the study.

Participant recruitment

I chose to conduct this research in Connecticut because of Connecticut’s statewide commitment to recovery-oriented care. Connecticut is at the forefront in the shift to recovery-oriented care in the United States, and although many states are following its lead, Connecticut continues to have the longest track record with established programs and sites that operate under the principles of the recovery model. Mental health programs in Connecticut have had over a decade to refine their approach, making these programs some of the most consistent and established in the United States. This made Connecticut the ideal location for research that aimed to explore the experience and perspective of mental health workers and consumers in recovery-
oriented care. Potential programs were recruited with the assistance of the Yale Program for Recovery and Community Health, which sent out a letter of interest to potential programs. A Community Mental Health Center responded to the letter of interest and invited me to recruit within their program. In order to identify potential study participants within the Community Mental Health Center, I provided them with two recruitment letters, one for mental health providers and one for consumers. Both recruitment letters were sent to clinicians within the program, who could then share the consumer recruitment letter with appropriate clients. Clinicians at the Community Mental Health Center were asked only to refer potential participants who did not have conservators of person. The recruitment letter included my email address and cell phone number so that potential participants could communicate with me about their eligibility for the study as well as contact me with any questions they might have had. If a client had been interested in participating in the study, the consumer recruitment letter had an area for clients to sign, giving consent for the clinician to pass on their contact information to me.

Recruitment letters were disseminated by the Community Mental Health Center in the beginning of September 2015. While some initial interest was expressed within the program, no potential participants contacted me. An amendment was submitted to the IRB to request permission to send out a second round of recruitment letters within the program. Additionally, the director of the Community Mental Health Center was contacted in an effort to identify any potential barriers to recruitment, with no success. Permission was granted by the IRB and a second round of recruitment letters were sent out in mid-November of 2015, but no potential participants were forthcoming.

The Yale Program for Recovery and Community Health sent out a second recruitment
email, this time targeting non-Department of Mental Health and Addiction Services (DMHAS) programs and a Regional Mental Health Board that had previously partnered with them in conducting research. Through this, six potential participants who met the study’s criteria for mental health consumers were identified. These participants were involved with the Regional Mental Health Board in the capacity of consumer advocates rather than clients. Two of the six potential participants removed themselves from consideration due to some uncertainty over identification with a diagnosis of schizophrenia.

In an effort to reach a wider audience of potential participants, I submitted another amendment to the IRB, expanding recruitment to Pennsylvania. The amendment was approved and a recruitment letter was sent out through the Allegheny County Coalition for Recovery. One program responded to the recruitment letter in Pennsylvania. They in turn disseminated recruitment letters within the program (see Appendix A). One potential participant was identified but did not meet criteria because they had never received a diagnosis. Recruitment was closed in May 2016.

**Development of the Semi-Structured Interview Questions**

The questions developed for use in the semi-structured interviews were intended as prompts rather than as a structure to be rigidly adhered to during interviews. The goal was to generate a conversation in which the participant’s individual experience of care might be explored with flexibility to pursue whatever threads felt most important to the participant. The questions were developed with the help of a peer-specialist, contacted through the Allegheny County Department of Human Services/System Transformation Unit, to ensure that the questions were clear and concise enough to meet the unique needs of the proposed participants.

Through discussion with the peer-specialist, it was decided to use the goals of the
recovery movement as broad guideposts for the interview questions. The process of developing the questions began with reading through the stated goals of the recovery movement as identified by Anthony (2000), Borg, Karlsson, Tondora, and Davidson (2009), Davidson et al (2007), Roe and Davidson (2007), Davidson, Schmutte, Dinzeo, and Andres-Hyman (2008), and Le Boutillier et al (2011). Each goal was examined and then a series of questions were generated that might explore and address how a participant perceived the stated aims of the goal, if and how they felt their needs were met in that area, and if there were differences in their experience across systems. For example, with regard to the recovery movement’s goal for consumers to “assume control” of their mental health care, some potential questions were:

- How has your experience of being “in control” of your own health care or mental health care changed over time?
- What makes you feel like you have control over your own care?

However, the results of this initial attempt missed the mark in several ways. The questions were too numerous for the scope of the proposed study but were also too pointed and not sufficiently open-ended enough to encourage conversation.

From this initial effort, I was able to simplify and refine the questions into a more open-ended series of five touch points that had the potential to elicit broader narratives of the participants’ experiences in mental health care (see Appendix D). The first question sought to establish the participant’s current mental health care in order to situate the interview and act as a comparison point. The intention was also to foster a more natural narrative flow, beginning with the participant recounting present experiences and then moving on to reflect on past experiences, as described by Davidson (2003). The second question was aimed at exploring any changes that participants had experienced in the care they received over time and to shift the narrative towards past reflection. Because any potential participant would have been receiving care both before and
after Connecticut had made the shift to a recovery model of care, this question created the opportunity to assess whether participants had experienced any difference between the two models. The third question targeted the participant’s experiences of differences in the care providers they had worked with over time. Similarly to the previous question, this created the opportunity to assess whether there had been any felt changes in how providers interacted with consumers before and after the implementation of recovery oriented principles. The fourth and fifth questions would ideally open up the opportunity for participants to explore how the care they received affected how they felt about themselves and about the world around them. The recovery movement’s goals are in many ways geared towards the end result that mental health consumers experience themselves and their mental illness differently. These last two questions sought to assess whether this shift had made itself felt in any meaningful way in consumers’ lives. Once I had this list of open-ended questions, one or two potential probes within each question were developed for use if necessary. Although I had initially intended to conduct pilot interviews, as described by Davidson (2003), the low response numbers made this impractical and so the interview questions were not piloted prior to their use in the final interviews.

**Data Collection**

Copies of the consent form were shared with the potential participants by email before the interview (see Appendix B). The Regional Mental Health Board through which potential participants had been identified offered to allow me to conduct interviews in an empty office on their premises. This location adhered to the requirement that the interviews be conducted in a neutral location so as to avoid an identification of the researcher and interview as occurring within the bounds of treatment because the Regional Mental Health Board was not connected to the treatment that the potential participants received.
Interviews with the four participants were conducted over the course of a single day. An hour and a half was allocated for each interview, although interviews were expected to be only about an hour in length. Interview materials included an audio recorder, consent forms (see Appendix B), an informed consent “quiz” (see Appendix C), and pen and paper for me to write down brief notes during the interview. When each participant arrived, I introduced myself and administered the consent form before beginning the interview. The informed consent form was reviewed with each potential participant, so that they were aware of the type of questions they would be asked, how their privacy would be protected, and how the data from the interview would be used. Afterwards, their understanding of the information contained in the consent form was assessed using an informed consent “quiz.” Participants were informed that the content of the interviews was not intended to touch on any experiences that were traumatic or painful in nature, although it was of course possible that the interviews might bring up traumatic or painful memories unintentionally. This was discussed with potential participants before they signed the consent form. A safety plan was discussed for use in the event that they did become upset, and they were asked to designate someone who could be called to come and assist them. After the consent form had been administered, I let them know I would begin recording and initiated the conversation by asking the first interview question (see Appendix D).

The interviews were semi-structured in the sense that the intention was not to adhere rigidly to the proposed questions but instead return to them as a framework for the interview when appropriate or in instances in which the participant had completed their previous response. I engaged with the participant by actively listening, reflecting back what I was hearing to ensure I had understood it correctly, and by asking questions to draw out further detail from their responses or to clarify if what they said was ambiguous. Some of the participants, Thomas and
Dolores in particular, required more active engagement to draw out information. The goal, although it was not always adhered to successfully, was to ask only open-ended questions that would allow the participant to elaborate on their experiences. The proposed interview questions were adapted to the content of the participant’s interview, for example in the interview with Thomas, questions four and five (see Appendix D) were adapted so that they reflected on Thomas’ experience of the Clubhouse in particular as that was the program that he was most deeply involved with at the moment although it was arguably not a treatment program (see Appendix E). The trajectory of each participant’s interview was of course unique, but some variation on each of the semi-structured questions was asked at some point in all four interviews. At the end of each interview, I opened it back up and asked if there was anything the participant wanted to share with me about their care or their experiences. This provided the participant with the opportunity to share anything with me that my questions might not have naturally elicited but nevertheless felt important to them. As the conversations came to a close, I asked the demographic questions about the participant’s current age, the age at which they began receiving treatment, and the number of treatment programs in which they had subsequently been involved. At times, the demographic questions, as can be seen in Dinah’s interview, elicited further narrative about their experiences of care beyond what had already been shared (see Appendix E).

**Data Analysis**

Before beginning the data analysis, each interview was transcribed verbatim from the audio recordings (see Appendix E). After the interview had been transcribed, the transcription was edited to ensure the participant’s confidentiality by removing or changing identifying information that they had shared during the interviews, such as the names of hospitals or providers with whom they had worked. At this point, I did an initial read through of the
interview during which I noted my assumptions and presuppositions about what I would find in the transcripts. In addition, I identified the themes that seemed to jump out at me in recalling the interview and in my transcription of the interview.

While some qualitative research does not call for further self-reflexivity, Walsh (1995) suggests that the researcher cannot ever fully know their own expectations and presuppositions with regard to research, which renders the traditional explicit acknowledgment of assumptions in qualitative methods insufficient in addressing those expectations that exist beyond the researcher’s awareness. To address this, Walsh (1995) suggests that qualitative research results “as described by a particular researcher” should be scrutinized in order to explicate the researcher’s position with relation to the phenomenon in question (p. 337). With this in mind, I followed the multi-step process suggested by Walsh (1995). The first step entails the explicit acknowledgement of the researcher’s a priori interests, expectations, and assumptions as described previously, the aim of which is the articulation of conscious aspects of the researcher’s approach. These aspects of my approach to the research will be explored in the Reflexive Analysis portion of the Results section. The second step calls for the researcher to reflect on the experience of interpretation or other analytic aspects of the research process as it happens. This will make up part of the Exploration of the Interview and Analysis Process and Key Themes in Each Narrative in the Results section. I began to address the first and second steps, as described above, during my initial read through of the transcriptions. The third step calls for an explication of the researcher’s implicit assumptions after the work of the interpretation or coding is complete. In this step, the researcher or an outside party analyzes the results of the research in the context of the researcher’s explicitly stated position as well as the researcher’s reflections (the product of step two). I will discuss this part of the process below.
After the initial read through of the transcribed interview, I then edited out my own comments and questions, stringing the participant’s sentences together to create the beginning of a narrative. Once I had this rough narrative, I read through it a second time in order to familiarize myself with the narrative and gain a sense of the whole. I then began to read through the narrative a third time, this time identifying and marking shifts within the narrative, or “meaning units,” and the themes associated with each unit. The delineation of these narrative shifts was somewhat arbitrary but identifies a change in tone or a movement from one thread within the narrative to another. For example, an unedited portion of the participant Thomas’ original narrative reads as follows:

Let's see. [Pause] Well, I started out in the partial hospital program. So, um, they had a psychiatrist there and he would prescribe medication and then I would go to what are called groups, activities, within the building, and, um, that--that was sort of, um, a place where--you c--i--it's sort of like a hospital, sort of. Where you're kind of recuperating, and then, I moved beyond that, to the Clubhouse. Well, the Clubhouse is the Fountain House model, I believe, recovery model, and it's--and it's about, um, work readiness, and, um, being responsible, and being independent. Oh, it's def--they definitely have, uh, staff there. In the partial hospital, um, I--I was more a patient. At the Clubhouse, I'm an employee. Um, at the time of partial hospital, I think I needed it.

In reading this portion of the unedited narrative, one can see that there is a shift where Thomas moves from speaking about the partial hospital program and the purpose it serves to talking about his experience of the Clubhouse. In identifying the different units of meaning here, I would mark the change as occurring in the following line, after the word “recuperating:” “where you're kind of recuperating,/ and then, I moved beyond that, to the Clubhouse.” The delineation of
meaning units for each participant can be seen in the Meaning Unit Transformation Tables (see Appendix G).

After identifying the meaning units, each unit was “transformed,” meaning that its content was pared down and clarified. Returning to the section of Thomas’ narrative that we looked at before, one can see the changes made in the “transformation” stage of the analysis to that same section of the narrative.

<table>
<thead>
<tr>
<th>Original meaning unit</th>
<th>Transformation 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Deep breath] Let's see. [Pause] Well, I started out in the partial hospital program.</td>
<td>I started in the partial hospital program. They had a psychiatrist there and he would prescribe medication and then I would go to what are called &quot;groups,&quot; which are activities, within the building. The partial hospital program was a place where you're kind of recuperating.</td>
</tr>
<tr>
<td>So, um, they had a psychiatrist there and he would prescribe medication and then I would go to what are called groups, activities, within the building, and, um, that--that was sort of, um, a place where--you c--i--it's sort of like a hospital, sort of. Where you're kind of recuperating,</td>
<td></td>
</tr>
</tbody>
</table>

While changes were made to the grammatical structure of the sentences and content was edited for clarity and flow, an effort was made to retain the participant’s word choices and individual style of speaking. When each meaning unit in the narrative had been considered, a second transformation was conducted with the units that could be further refined.

Once this had been completed, I reordered the meaning units, creating a more cohesive flow in the narrative while still maintaining the participant’s own language. Although some researchers re-write such narratives in the third person, I followed Sells, Topor, and Davidson’s (2004) approach, which emphasizes the importance of the researcher developing empathic bridges to the narrative. In order to facilitate this process, I maintained a first person point of view in the narratives. The authors argue that although the importance of narrative structure has been explored to some degree, the third person presentation of narratives are at greater risk of
objectifying the participants and allow for a greater distance from the emotional impact of the narrative. This may be a particular risk with the narratives of individuals identified as psychotic or tangibly different. Once we have begun to distance ourselves from a narrative, it is difficult to re-build the empathic bridge.

After re-ordering and “streamlining” the participant narratives, I reflected on each meaning unit in order, considering each unit’s significance to the description of the experience. Part of this process included exploring the implicit as well as explicit meanings of these statements and distinguishing between similar but different meanings, as well as reflecting on how the multiple themes related to each other and to the whole. I identified what themes and meanings occurred in each narrative and then compared these across the four participants in order to find the common threads across narratives. This required attention to the content associated with each thematic label to ensure that there was commonality in the underlying meanings. I then considered the themes that were unique to an individual narrative, attending to the ways in which that particular participant’s experience differed from those of the other participants.

At the end of the formal analysis, I undertook step three of Walsh’s (1995) process of reflexivity. In this step, the researcher or an outside party analyzes the results of the research in the context of the researcher’s explicitly stated position as well as the researcher’s reflections (the product of step two). The process and results of the third step informed the write up of my analysis and will be explored in a discussion of my preconceptions and conscious biases.
Chapter Three

Results

In the following section, I will discuss the results of the qualitative analysis, beginning with a description of each participant, my experiences and impressions during each interview, and my experience and impressions of the analysis process for each narrative. I will also lay out the key themes that I identified in each narrative. From there, I will explore the points of thematic convergence across the narratives and describe how these themes manifest in each narrative. I will then talk about the themes that are unique to individual participants and other notable differences across narratives. The last portion of the Results section will address my reflexive analysis, which will begin with a summary of my a priori interests, expectations, and assumptions. I will then return to a description of my experience in the interpretation and analysis phase of the research. Lastly, I will present an explication of the results in the light of my implicit assumptions.

Exploration of the Interview and Analysis Process and Key Themes in Each Narrative

Thomas. Thomas is a 56 year old, single, Caucasian man. A physically large man, Thomas nonetheless took up very little space in the interview room. His voice, although clear and audible, was pitched low and he spoke slowly and thoughtfully, often pausing before responding to my questions. Thomas wore his dark hair cut close to his head. He was dressed plainly and comfortably in long loose pants and layered loose shirts. Around his neck, Thomas wore a number of colorful prayer beads, rosaries, and amulets. Although he seemed to openly share his opinion about his treatment experiences, Thomas nonetheless appeared to be somewhat anxious about not causing offense or expressing too extreme a view, moderating many of his

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1 The names and identifying details of all participants have been changed or removed from the narratives and interview transcripts to protect their privacy.
statements. At the end of our interview, he expressed the anxiety that he might not have adequately answered my questions.

Thomas began receiving treatment in 1983, when he was 23 years old and has received care in both inpatient and outpatient settings. Thomas is currently employed as a chef at his local Clubhouse, where he has worked since 1998. In the past, Thomas has received care from a psychiatrist, psychotherapist, and worked with a case manager. For the past 15 years, he has received treatment from a psychiatric nurse and no longer works with a case manager. He currently lives with his parents, whose aging is a major concern for Thomas.

My experience and impressions during the interview. During the interview, Thomas appeared to be somewhat shy and tentative in his responses, which were quite measured and limited. His affect was, for the most part, flat and he rarely imbued his words with much emotion. There was one notable exception to this, which took place during his exploration of his fear for the future in relation to his aging parents. When speaking about this fear, Thomas appeared visibly shaken and near tears. During the interview, his responses seemed to center on the concrete details of his current situation and position at the Clubhouse rather than addressing his past experiences. For the most part, he avoided offering details about his time in the partial hospitalization program and shared very few examples of his experiences of care in general. Compared with the other participants, Thomas did not speak about the different kinds of care he had received nor did he reflect on the situations that had occurred which precipitated treatment. I found myself frustrated at times during the interview by the lack of examples and the paucity of personal content almost as though he was speaking about a generalizable experience within the kind of care that he has accessed over the years rather than about his own experience within that care.
My experience and impressions in the analysis. Contrary to my experience in the interview, I found myself much more attuned to the delicate balances and personal growth that Thomas described through the process of analysis. Although it is true that his responses were more directly structured around the concrete details of his current situation and position, significant information about his experiences of care can be drawn from what he did say. I am thinking here of a sense of being without agency that accompanied many of Thomas’ descriptions of times in his life when he had been less “functional.” There is a feeling of helplessness and powerlessness within those descriptions that is telling in understanding aspects of his experience that were not explicitly shared. Thomas hinted at the ways in which the higher level of support and the restrictiveness of the systems he was in at those times felt perhaps rigid or unyielding, while also being necessary to the emotional state in which Thomas found himself.

Similarly, Thomas’ descriptions of past supports that no longer exist points to some of the gaps that occurred in the process of systems change or that reflect a pre-existing failure to meet the needs of a specific group of individuals who may fall between levels of care. In his comments about this, Thomas talks both about these absences in support where he had previously had it and about his own growth and stability, which have rendered this lack manageable for the most part. Thomas tends to first describe these gaps and then follow up with the observation that he now feels capable of managing the majority of these issues on his own. This sense was echoed, if not directly addressed, in the interviews with Dinah and Dolores.

Key themes that stood out in Thomas’ narrative. In the interview, Thomas speaks about the gradual shifts over time in the way that he was treated and perceived by the staff at the Clubhouse. The theme, Transitioning from Patient to Employee, is threaded throughout his narrative. This transition was framed as a positive development of skill, an increasing ability to
hold greater responsibility and handle a higher level of stress, and a lessening of the support available to him. This shift also represents a change in others’ expectations of Thomas. He says, “The staff aren’t so patient with me but with the other clients they are. The staff expect more out of me because I’m an employee.” Here Thomas speaks to a certain kind of loss in his interactions with the staff at the Clubhouse, people who had perhaps previously engaged with him with a greater degree of gentleness and understanding. Thomas observes and can measure the differences in how he is treated in comparison to other members of the Clubhouse who are not employees. However, there is also some pride contained within this observation. While Thomas is aware that he is treated differently and with less patience, that difference in part indicates that the staff holds him to a higher standard and believe him capable of meeting this new standard.

This is also connected to the theme in Thomas’ narrative of *Having Responsibility and Doing Good Work*. Although Thomas feels the stress and pressure of his work, he feels capable of what is asked of him and feels satisfaction in his ability to live up to the standards that are set for him in his job. Thomas’ pride is clearly reflected in his description of his yearly evaluation, “They do a yearly evaluation of me and my evaluation was near the top, like most of my marks were the highest possible. I feel good, I feel like I’m doing a good job.” Thomas’ previous employment experiences often ended in him being terminated due to an escalation of issues related to his mental health or because he “didn’t live up to their expectations.” The feedback that he receives from the Clubhouse is an important confirmation that, despite difficult circumstances, he is able to handle the responsibility given to him and does the work well.

However, Thomas makes clear that he doesn’t always feel able to live up to the standards set by his employers and the staff at the Clubhouse and that this can be painful. He says:

I do feel somewhat limited by my disability. I’d prefer that maybe the staff not be so
judgmental or critical when I make a mistake. But, at the same time, I think they’re trying to create an environment where you experience what you would in the community if you had a job there.

While Thomas values the responsibilities given to him, these expectations can make it difficult for him to access the emotional support and acceptance that the Clubhouse once represented for him. Thomas’ exploration of the Clubhouse’s prioritization of *Work-Readiness rather than Emotional Support* is another major theme in his narrative.

The lack of a clear source of emotional support isn’t limited to Thomas’ position at the Clubhouse and the theme of *Being Self-Sufficient but Needing Support* echoes through Thomas’ reflections on the changes in his mental health care over the years. Thomas says:

*I think that I don't need as much outside support as I did in the past. It feels sort of good, in a way, to be self-sufficient. But at the same time, I think that once in a while I might run into a problem that I can't handle and that I might want to discuss it with someone.*

Thomas, like many other individuals with mental illness who fall between levels of care, has access to some practical services, but has needs that are no longer met by what he does receive.

Beyond the shifts in care that Thomas has received over the years as both his needs and the systems he has accessed have changed, Thomas also speaks to a reoccurring experience in interacting with mental health professionals that took place across mental health care settings. This is reflected in the theme of *Being Made to Feel Small and Being Disregarded*. One of the few explicit examples that Thomas gave in the interview pertained to this theme and took place while he was in the partial hospitalization program. He says:

*The psychiatrist at the partial hospital program came from the prison system; he was very stern and he had a bad temper . . . it was hard working with him. One of the things that*
came up when I was in the partial hospital program was that they put me on some medications that didn't agree with me. When I asked to be changed to something else, they didn't listen to what I said. They disregarded my input and so I struggling for a long time with side effects from the medication.

This was a theme that was also present in Dinah and Dolores’ narratives and points to a common experience, particularly prior to the shift towards recovery-oriented care, of the client’s experience and input not being valued in treatment planning.

Thomas also describes interactions with staff that feel disempowering and pejorative. As an example, he shared his experience with one of the prior directors at the Clubhouse. He says:

She was . . . sort of hot tempered and she could get very angry. She had a way of making me very uncomfortable when I did something wrong. She would raise her voice and she had an angry tone. She just had a way of making me feel small I guess you could say.

Although not explicit, Thomas’ description of how the Director made him feel hints at how the behavior of staff towards him, and perhaps other clients, can be imbued with impatience or a lack of respect when things are difficult or do not come easily to the client.

Despite this, Thomas identifies the Clubhouse as a “safe place” and highlights the importance of this throughout his narrative. The theme of The Importance of a Safe Place is in part an appreciation of the Clubhouse as an environment in which mental health consumers can feel secure, but is also an illustration of the ways in which many spaces do not feel safe for mental health consumers. Thomas explains:

I feel like I'm in a safe place where I am. I feel more secure at the Clubhouse. I think that if I were to leave that environment and go out into the community, I might be treated in the same where I was before, where I was put down. Or maybe, if I was in a situation
where I was having some kind of psychotic symptom, people might not understand what's going on and there might be some kind of serious consequence to that.

While Thomas’ experience of the Clubhouse may not always be positive, it is one of the few places in which he knows his experience and behavior will be understood and handled appropriately. In addition, it is one of the few places he can seek employment while openly identifying as an individual with mental illness without fearing the consequences. Thomas says:

I did have some trouble when I was working outside of the Clubhouse. Some people, when I disclosed my illness to them, abused me. People, for some reason, put me down because I had a disability. The Clubhouse is a very safe place. For the most part, people understand where you're coming from.

Although even the Clubhouse is not a space devoid of judgment, Thomas can know that he will not be rejected or abused due to his mental illness within the Clubhouse community. Beyond the safety offered by the Clubhouse, its emphasis on work-readiness has succeeded in providing Thomas with a sense of security. The theme of *Having a Sense of Stability and Security* highlights Thomas’ increased confidence in his ability to support himself and meet his needs should something change in either his employment or his living situation with his parents. Thomas says:

I feel like I have a marketable skill as a chef. So, I feel like if something happened or for some reason the program closed or if I was laid off, that I could get work as a cook. So there's a sense of stability and security.

Although Thomas’ previous employment experiences ended in his termination, he has now successfully worked for a number of years in an incredibly high stress position. These themes are summarized in Table 1.
Table 1

*Themes in Thomas’ Narrative*

<table>
<thead>
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<th>Theme</th>
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<tr>
<td>Proving Myself to Others</td>
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<td>Transitioning from Patient to Employee</td>
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<td>Belonging and Responsibility</td>
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<td>Having Responsibility and Doing Good Work</td>
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<td>Independence and Functioning</td>
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<td>Being Self-Sufficient, But Needing Support</td>
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<td>Work Readiness Rather Than Emotional Support</td>
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<td>Experiencing a Lack of Support</td>
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<td>Planning for the Future</td>
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<tr>
<td>Getting Involved with Cooking</td>
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<td>Support in the Past</td>
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<td>Experiences in the Hospital</td>
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<td>Staff are Dictatorial</td>
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<tr>
<td>Wide Range of Recovery</td>
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<td>Being Led Versus Leading</td>
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<tr>
<td>Being Made to Feel Small and Being Disregarded</td>
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<tr>
<td>Clients Being Disciplined</td>
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<tr>
<td>Being Advised Instead of Punished</td>
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<tr>
<td>Staff Need to Provide Support and Be Patient</td>
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<tr>
<td>Being Listened To</td>
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<tr>
<td>Limited by my Disability</td>
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<tr>
<td>My Confidence Comes from Myself</td>
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<tr>
<td>Wanting to Provide Better Food</td>
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Leah. Leah is a 70 year old, partnered, Caucasian woman. She was tall and slender and although she appeared somewhat physically frail, Leah’s body language and facial expressions were active and emphatic. Leah spoke rapidly and with great emotion, moving from one topic to another so quickly that it was sometimes difficult to follow where one ended and another began. She appeared comfortable in commanding the space and in advocating for her needs, asking that
we readjust the seating arrangement to better accommodate her physically. Leah was dressed simply and comfortably in long pants and a loose, long sleeved shirt. She seemed to have important aspects of her experience in mind even before we began the interview and she repeatedly mentioned experiences she intended to elaborate on later in our discussion.

Leah began receiving treatment when she was approximately 15 years old and has received treatment in both outpatient and inpatient settings. She is currently employed at a local mental health advocacy organization. In the past, Leah has received care from private psychiatrists and psychotherapists. She has been working with the same psychotherapist and psychiatrist since approximately 2011.

*My experience and impressions during the interview.* During the interview, Leah’s pain and anger over her experience with a sexually predatory psychiatrist and her experience as a pregnant teenager in the mental health care system were very present. In many ways, her painful life experiences were interwoven with her experiences in mental health care so that it was difficult to separate one from the other and perhaps also difficult to know how one colored the other. Also palpable was Leah’s pride in actions she had taken over the years that resulted in her reclaiming her agency, sometimes in the face of overwhelming odds. Although not in detail, Leah talked about the satisfaction of finally being in therapeutic relationships that felt good and felt valuing of her experience and self-understanding.

However, Leah’s narrative was at times quite difficult to follow and the timeline of her experiences was the most difficult to parse of any of the participants. In the same way that her traumatic life experiences and her experiences of mental health care seemed interwoven, the traumas themselves seemed connected and to lead from one to another in the narrative so that they were hard to place in time. I had the sense that there were significant and relevant parts of
the narrative that I was unable to explore purely because of the difficulty of parsing out the threads of her speech during the interview.

**My experience and impressions in the analysis.** I also struggled to fully understand the complexities of Leah’s accounts in the analysis phase. I was, at times, uncertain of the rough timeline I created within the narrative, but overall felt as though the impact of her experience came through regardless of the chronology. Staying true to Leah’s language also felt difficult at times because of the way in which her sentences were structured. As mentioned previously, Leah’s accounts of her traumas often seemed to flow into one another, making it hard to know where one ended and another experience began. In the process of analysis, it was necessary to clarify and refine through transformation, which included a somewhat arbitrary delineation of these different experiences. Although transformation is, of course, part of the process, I found it difficult, with all of the interview material, to tread the middle ground between clarification, translation, and reinterpretation. I had the sense that there is a necessary kind of violence to the process of analysis. With all of the participants, but in particular with Thomas and Leah, I had the feeling that I had not even managed to scratch the surface and was presenting a terribly incomplete picture.

**Key themes that stood out in the Leah’s narrative.** Early in our interview, Leah began to describe the numerous traumas she had experienced in the course of her life so far and how these had affected her mental health and her overall well-being. The general theme of *Trauma* plays an important role in how Leah frames her own shifts in mental health and her experiences of care. Leah’s involvement with mental health care began with her father’s struggles with mental health issues:

My family got uprooted from the state where we'd been living and we went back to the
city where I was born. My father had mental health issues too and he was hospitalized and ended up in the state hospital. It was a nightmare. My family fell apart and we left in the middle of the night, my mother, sister, and I. We left the house, my dog, everything I owned, and came back here. We had no place to live, so we stayed with my aunt and uncle.

Leah expresses a sense of upheaval and impact (losing her sense of home) and uses a phrase that repeats throughout her narrative, “it was a nightmare.” This phrase in Leah’s narrative seems to convey a loss of stability in both her internal and external worlds and a sense of assault by outside circumstances. “It was a nightmare” appears to be both a descriptor of her experience of the situation and the impact it has on her mental health.

Leah expresses a sense of frustration with the repeated traumatic occurrences with which she has been faced and the emotional repercussions of these experiences. She says:

I’ve had multiple, multiple, multiple, uncountable traumas in my life. Sexual traumas, losses, hospitalizations and treatments that were not good, and I’ve been in two fires. I just keep running up against the trauma. I seem to get over it and then something else comes up in my face and brings it up. I have screaming nightmares.

During the interview, as Leah recounted several of her experiences of sexual assault, I had the sense that there was too much to comprehend. The memory or recounting of one trauma led directly into her speaking about another and about her failure to function following each onslaught.

The central experience that Leah shares was about a relatively recent situation, which involved a psychiatrist she had worked with for a number of years making sexual advances towards her. The sense of betrayal and violation that Leah feels as a result of this experience was
strong in the interview and she talks about the aftermath of the experience as a particular low point for her. Leah says:

After a time, I became fully aware of what was happening. I did a lot of god-awful reflection and “what the hell do I do” and “who do I turn to.” I went to visit my family and spent most of the time holed up in my room crying . . . I mulled it over a lot and I got enraged. I said, “This is really, really bad.”

Although Leah identifies this experience as having been “abuse in the system,” in many ways it sounds as though the mental health care system she was in at the time rallied in support of her and her accusation of the psychiatrist was followed up by the hospital in which he worked.

Leah’s other particularly traumatic or painful experiences in mental healthcare are situations in which she experienced a lack of support or a lack of care that felt proactive and productive when she was most vulnerable and in need of help. These experiences represent the theme of *No Support, Just Horror*. The first time that Leah was hospitalized was when she was 19 years old, unmarried, and pregnant. Having realized that she would not be allowed to keep her child, Leah threatened suicide, either out of true hopelessness or, as she thinks, in an effort to convey her distress.

So here I was, in this ancient city hospital. I'm eight months pregnant on a psych unit. This was in the 1960s, so there was this long, dark hallway. There were nuns who were patients there, sitting on the edges of their bed. And here I am, knowing I'm going to lose my child . . . So they put me in this hellhole. I was hysterical. All I did was cry. It was just god-awful.

Leah describes being hospitalized in response to her understandable pain over the potential loss of her child. Rather than having her distress treated as a natural outcome of her situation, it was
pathologized and treated with hospitalization.

Leah speaks about the horror of her experiences in inpatient hospitalization, both at the time of her pregnancy and afterwards. The image she paints is almost cinematic in its fulfillment of the worst stereotypes of inpatient hospitalization.

It was so institutionalized. It was horrific. The beds were so close. People were hallucinating and crying and sobbing all night. We wandered around the day room, you know, the stereotypical wandering around the day room. People could smoke, so there's a little thing on the wall so they could light their cigarettes. There's no place to sit. There's one or two couches that everybody's vying for. I got shock treatments with no freaking anesthesia. There was one person, or perhaps two, that were kind. Everybody else was just horrible.

Although Leah shares elsewhere that she has had some experiences of hospitalization that were more positive, overall the image she creates of inpatient hospitalization is of a place that exacerbated the sense of trauma, distress, and isolation which led her to require a higher level of care in the first place.

In the face of Leah’s experiences of trauma and of treatment that exacerbated her distress, one of the most prominent themes in her narrative was of the pride that she took in the instances where she had taken steps to regain her agency in times of distress. I have identified this theme as *I Take Great Pride*. The first example that Leah identifies in which she took such a step was during her hospitalization while pregnant as a young adult. As explored above, Leah experienced the hospital as nightmarish and unbearable. She recounts the steps she took to get herself out of the hospital:

So I said, the hell with this. I am not staying here. I got a Kotex pad and I put a little nick
in my arm, somehow, with something, and I put the blood on the pad. I was savvy; I
dunno how I even thought of that. And you know what they did? They took me out. They
put me on a regular unit.

Leah expresses pride in her ability to find a way out for herself even in the midst of debilitating
despair and an intense sense that she is without support. Not only did Leah’s attempt succeed,
she was eventually able to get herself out of the hospital altogether for the remainder of her
pregnancy.

In the instance of Leah’s experience with the psychiatrist who made sexual advances
towards her, after realizing what was happening, Leah alerted the hospital where he worked. She
explains:

I happened to be in a DBT program at the hospital the psychiatrist worked at, because I
was starting to slide, but I wasn't identifying exactly what was going on. When I went in
for the intake, I said, “Somebody on staff is abusing me. And he's diverting meds.” I
thought they were just going to gloss over it. The next time I came in, a bigwig, the
Director of Medicine or something, was there. He said, “Tell me. Right now. Tell me
what is going on.” I told him.

Not only did Leah take the monumental step of notifying the staff, her attempt to take action paid
off. Leah indicates the difficulty and importance of the step she took, pointing out that the
experience of sexual abuse is horribly familiar to her and she might easily have allowed herself
to suffer his overtures silently. She explains the change in perspective that this required of her
and how hard it was to do this in the face of her history. Leah says:

I take great pride in the fact that I spoke out. I've been sexually abused many times. First,
I feel compassion, “Oh, I want him to get help.” . . . And then I changed my mind real
fast. It’s like, okay, I ain't gonna take this from this jerk. Rather than allowing herself to continue being victimized, Leah prioritized her own well-being. Leah’s bravery in reacting to this situation is underlined by the fact that she chose the option, when offered the choice by the director of the hospital, to confront the psychiatrist herself. She says:

I walked into his office and I stood there, proud and tall, and I said, “You have done harm.” You know, the Hippocratic oath. And I said, “Dr. So-and-so knows and he knows that you've been taking those medications and diverting them for yourself. And Dr. So-and-so is going to be speaking with you.” He blanched and leaned back in his chair and said, “I’m sure he is.” I said, “I never want to see you again or talk to you. I am done and I'm outta here.” And I walked out.

While undeniably difficult, Leah’s personal confrontation of the psychiatrist provided her with the opportunity to convey to him, explicitly, both the effect and repercussions of his actions. Leah’s account of herself as standing “proud and tall” makes clear what a momentous moment this felt like to her.

Despite her pride in how she was able to handle the situation, the experience created a traumatic association with the idea of pursuing psychiatric care. Following the experience, Leah had a difficult time engaging in mental health care again. Happily, rather than simply turning away from care altogether, she was able to identify that she wasn’t comfortable working with anyone in town and so outreached to find other resources. Although Leah was wary of beginning therapy again, these relationships have proven fruitful and supportive beyond Leah’s expectations. She says:

I went to therapy not knowing if it was gonna be a good match. It absolutely is. It's just a
joy . . . She and I are just on the same page . . . So it's just so fun and she's so non-labeling. I don't even see the DSM sitting around her office, which I like.

Leah pinpoints aspects of care that are important to her at this point in her life. Finding and experiencing care that lives up to these needs represents another major theme in Leah’s narrative, *Being Respected and Giving Input*. Leah talks about the difference between the care she receives now and the care she has received in the past not just as a change in her own needs, but also as a shift in approach. She says:

I've been in treatment, on and off, since I was 14. The care that I receive now compared to the care I've received in the past is like day and night. The kindness and letting me have my own input. I'm still on a little bit of medication, but I discuss it with the psychiatrist and she says, “Well, what do you think?” We talk and she lets me give input.

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<th>Table 2</th>
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<tr>
<td><strong>Themes in Leah’s Narrative</strong></td>
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<tr>
<td>Being Respected and Providing Input</td>
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<td>Treatment Varied, but Started to Improve</td>
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<td>Sources of Support</td>
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<td>A Good Partner</td>
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<td>Beginning to Thrive Again</td>
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<td>I Take Great Pride</td>
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<td>No Support, Just Horror</td>
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<td>Trauma</td>
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<td>The Bad Doctor</td>
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<td>Finding Help</td>
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<td>I Just Couldn’t Function</td>
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<td>A Zombie</td>
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<td>Loss</td>
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<td>Things Turned Around</td>
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Table 2
Leah describes a relationship that is built on mutual respect and a prioritization of Leah’s desires for the direction of her care. These themes are summarized in Table 2.

**Dinah.** Dinah is a 51 year old, lesbian, partnered, Black woman. She was tall and broad and, although Dinah held her body still during the interview, her face and voice were deeply expressive. Dinah was dressed in loose-fitting, colorful clothing and a few simple pieces of jewelry and her long hair was thoughtfully arranged. For the most part, Dinah appeared quite confident and comfortable in the interview, suggesting before we began that I do a sound check on the recording device and seeming to speak very openly and frankly about her experiences, often with great humor. However, particularly at the end of the interview, Dinah also repeatedly apologized for the strength of her expression and for “not letting me get a word in edgewise,” which suggests she may have felt a self-consciousness that was not readily apparent. Alternately, this may reflect Dinah’s attempts to protect against the risk of being a large and commanding woman of color and the ways in which that makes her vulnerable.

Dinah began receiving treatment in 1981, when she was 17 years old, and has received care in both inpatient and outpatient settings. She is involved in the Hearing Voices Movement and is employed at a human rights agency, with which she has been involved for a number of years. In the past, Dinah has received care from a psychiatrist and psychotherapists. Dinah is currently receiving treatment only from a psychiatrist, having ended her most recent psychotherapy three months ago. She has worked with this psychiatrist since approximately 2005.

**My experience and impressions during the interview.** During the interview, Dinah spoke with feeling and certainty about her experiences. While there was a great deal of pain and shame associated with these experiences, Dinah made a point of saying that she was willing to speak
about them in the hope that it would make a difference for others. At times, she became very emotional when speaking and identified feeling, though she did not appear so, agitated and angry. This interview, in many ways, most adhered to my pre-conceived notion of ideal material. Not necessarily because I had hoped or assumed that people would have had the experiences that Dinah describes, but rather because, perhaps as a result of her training and professional experience, Dinah was able to speak eloquently and passionately about the kinds of treatment and negative experiences she had had in mental health care. This interview was in many ways the most straightforward and Dinah was the easiest participant to draw out. She had clearly thought at length about these experiences and could explicitly identify how they had felt and what had not felt good. I do not believe that Dinah had actually had more involvement with the mental health care system than the other three participants, but she spoke vividly about the experiences she had had. While Leah was able to paint a detailed picture of the environment within the hospitals, Dinah spoke more directly about how she had been treated by care providers.

**My experience and impressions in the analysis.** Dinah’s narrative needed the least interpretation of the four, because she was so clear about the impact, negative and positive, of her various experiences in mental health care. Her narrative also spanned the greatest breadth of material, speaking to hospitalization, restraints, psychotherapy relationships, the impact of family involvement in care, medication, client rights, racial issues within mental health, and the experience of hearing voices. I felt more confident of the picture I was able to develop of Dinah and her experiences than with other participants. However, as with other participants, staying true to Dinah’s language was difficult because of her sentence structure and the transformation stage of the process felt challenging to negotiate. Because her interview needed less
interpretation, I may have erred on the side of preserving more of her original sentence structure than with other participants.

**Key themes that stood out in Dinah’s narrative.** In the interview, Dinah speaks about the idea that one’s interactions with others are influenced by one’s appearance and ability to behave in ways that others find acceptable. This made up the theme *Treatment is Based on Appearance.* In talking about her experiences in mental health care and trying to understand why things had happened in the way they had, Dinah imagines that some of the treatment she received was in reaction to her physical presentation rather than her behavior. She explains:

> At the time I was restrained, my hair was in locks, you know, I might have looked bigger, I weighed more, I'm not saying there's a difference, but I'm saying there's a difference in how you're treated. And I would say I was restrained by at least seven or eight people, most of them were men.

Dinah is clearly aware that the color of her skin and her physical appearance has the potential to seriously impact how others perceive and treat her. When speaking about a conflict with an employee at the Department of Motor Vehicles, Dinah talks about having to be particularly careful about her choices in public interactions because of the possible outsized repercussions of her becoming visibly agitated.

Beyond her physical appearance, Dinah also speaks about the performative nature of the interactions required of mental health consumers in navigating mental healthcare. She says:

> I learned that there's a certain way a patient has to talk in order to be heard and in order to have what we desire to have . . . [I] learned quickly that when you go through the many mental status exams that there are certain ways you have to answer those questions and there's certain ways you have to look in order to for the providers to view you a certain
Dinah points to an aspect of mental healthcare that has been described elsewhere, wherein consumers quickly learn to behave in specific ways to elicit positive outcomes (or avoid negative ones). This often involves avoiding mention of hearing voices, speaking in particular tones of voice, or using particular words. This theme in Dinah’s narrative is a reminder that mental health care is often experienced as a series of hoops through which consumers must jump.

Throughout her narrative Dinah speaks about *Treatment that is Unwarranted, Dehumanizing, and Traumatic*. For Dinah, the experience that epitomizes this theme is being restrained while in the hospital. She says:

> I like to think I’m a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. I think none of us, there's not a single solitary soul, that I feel deserves to be placed in four-point restraint.

Dinah makes clear that she feels restraints are never appropriate, but she also takes pains to highlight her sense that her behavior at the time of her restraint did not merit that intervention, even when it is perceived as an acceptable choice. She says:

> When I say that I didn't do anything to warrant those restraints, I mean that . . . I wasn't, like, escalated . . . I had gone into a patient's room in a distressed moment. I was having an experience where I was having a dream . . . where I felt like my brother was talking to me and I went into the patient's room and I rubbed his head and I called him my brother’s name and that was it . . . I didn't have on any clothes at the time and had been going through something. But I wasn't a danger to the patient and I didn't do anything that was violent. They asked me to go back to my room and I . . . didn't want them to tell me to go
back to my room . . . But it didn't warrant eight people throwing me down on a gurney and restraining me for a night.

Here Dinah describes a situation in which restraint was seen as an acceptable tool and used in a situation that could perhaps have been handled differently. If, as Dinah says, she was not a danger to herself nor to others at the time of her restraint, the experience implies that restraint might be used purely because the consumer’s behavior is inconvenient or objectionable, a distinction that is far more arbitrary.

Beyond feeling that restraint was inappropriately used in her case and should not be used in general, Dinah also speaks about the actual experience of being restrained. She says:

When I was a child, I was molested and no one listened to me . . . So, when I was restrained, it felt like my body wasn't my own and no one was available to hear me or that they didn't care how I felt. It felt punitive, not like it was healthcare.

Dinah clearly expresses the traumatizing potential of restraint and how this comes into play for consumers already in extreme distress.

Another theme repeated through Dinah’s narrative was that of Rights Not Being Communicated or Being Obliterated. As someone who later learned a great deal about client rights through her work in advocacy and in pursuing her degree, Dinah reflects back on her own experiences in hospitals and identifies a failure in the communication of her rights. “It wasn't like the stuff I learned later about patients' rights being posted and having to know that you have the right to refuse.” At the time, Dinah was unaware that having gone to the hospital voluntarily, she was free to leave at any time. She felt that, “The patients' bill of rights is something that was obliterated. My rights were obliterated.” In the process of learning about these standards in mental health care, Dinah observed a disconnect between what is taught and what she
experienced as a patient.

Throughout our conversation, Dinah expressed frustration with her choice to take medication, while also reflecting on the reasons she had done so and continues to do so. This presented a broad theme of Ambivalence Around Medication. Within that broad theme, there were two separate threads that emerged. The first of these has to do with Dinah’s contradictory feelings over The Impact of Choosing to Take Medication. Dinah’s internal conflict about choosing to take medication is clearly illustrated in her description of the first time she experienced the effects of medication. She says:

I was given Haldol when I was restrained and the next day I actually did feel better, calmer. One of my friends came to visit me and I said, “What happened?” Or “Why am I feeling so much calmer?” He said, “You were medicated.” And I said, “Oh, is that the impact of medication?” And he said, “Yes.” I said, “Maybe I should take it to get out.”

While Dinah initially describes feeling “better” and “calmer,” she suggests that her decision to take the medication was a strategy to get out of the hospital, rather than a treatment choice. These conflicting feelings are also laid out in her reflection on the overall effects of medication in her life. Dinah says:

Really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years.

Although Dinah says that her experience of psychiatry, and presumably medication, is primarily negative, the benefits, if we may be allowed to call them that, of her first experience with Haldol in the hospital suggest that there may be more nuances to her experience of medication. This is hinted at in her admission that “there’s been some positives.”
Dinah’s negative experience of psychiatry and medication may be better understood in the context of why she has made the choice to take medication and the fact that her own beliefs are so in conflict with those of her physicians and family. This is represented in the theme *Desires About Medication Aren’t Respected.* Dinah explains:

I initially took medication to get out of the facilities and then to satisfy my family, who, like I said, believed that you should take medicine if you have a mental illness. But it's also been my own doing and I take full responsibility for continuing to take the medication even though I feel some kind of way about it and don't think it’s effective. It has never stopped the voices that I hear.

While Dinah has, perhaps, experienced some benefit from medication, it has not been the cure-all or solution that her family seems to believe it might be. Knowing that it has not stopped her from hearing voices and that she has experienced serious side effects from the medication, Dinah may feel that whatever benefits she might gain from medication do not outweigh the costs. And yet there are few other options offered to her or to her family. Because of this, Dinah is caught in a bind wherein she either continues to make the choice acceptable to her family or make the choice in which she believes.

Although Dinah does not yet have full support for the choice she would like to make, she does identify ways in which the mental health care system has changed over the years. These reflections represent the theme *Mental Health Care has Changed, but the Status Quo is Hard to Change.* Elsewhere in the narrative, Dinah describes her evolving relationship with her current psychiatrist, who she feels is willing to work with her on her terms and respects her feedback. However, Dinah recognizes that the changes in her work with the psychiatrist are not reflected across the board. She says:
We have a voice and I have a voice today that I didn't feel was being heard by service providers before. I still think there's some service providers who don't hear me when I speak, who don't recognize that we do have choices. As people with a mental health condition we have a choice. Ultimately the choice should lie within us.

A baseline acceptance that consumers have choices is not yet so universal that it can be depended upon or taken for granted. Dinah communicates a sense that she is not really seen or acknowledged by some of the providers with whom she works.

Even well meaning, generally conscientious providers can struggle to consistently integrate changes that are made in policy and to maintain a continuing engagement with the client’s treatment plan and goals. Dinah says:

Even with the third therapist I had, an old treatment plan was still being used, just to get you to sign it so that they could get funding. Probably it was partly due to my lack of insistence that I be a part of the treatment planning. I think that still is an area that needs to be addressed . . . Even me, knowing and teaching it, I still go to a facility and on the most recent treatment plan I signed, I really just signed it. We didn't have a conversation first about what my goals are, although she knew that I want to get a job as a social worker, that's not in there.

Although Dinah had a good working relationship with her therapist and a strong understanding of what should be covered in her appointments with the therapist, these gaps still occurred in their work together. Dinah’s narrative acts to underline how easily steps like these can fall to the wayside. She makes clear that, although there have been substantial shifts in mental healthcare and in the way some providers engage with clients, there are underlying aspects of mental health care that have continued unchanged.
Dinah’s changing relationship with her psychiatrist and the positive interactions she has had with certain care providers make up the theme in her narrative of Treatment that Feels Humane. This theme contains examples of working relationships that are closer to the respectful and collaborative approach that Dinah is seeking from her mental healthcare providers. In the context of her work with the psychiatrist, Dinah says:

He's not certain what the outcome will be with me, but at least he's willing to work with me . . . he's been my psychiatrist for all this time. And so he's seen my growth and development as a human being and as a professional and I think that has probably made a difference for him.

Dinah credits their length in time working together and the positive changes in her that the psychiatrist has seen with his willingness to work with her as a partner in decision making about her medications. Her relationship with the psychiatrist represents a shift from experiences where client feedback was not acknowledged and their involvement was discouraged.

A related theme in Dinah’s narrative is The Importance of Therapeutic Connection. This theme contains several smaller threads including Therapeutic Connection, Lack of Therapeutic Connection, and Differences in Therapists’ Approach and Ability to Listen. Dinah speaks at length about how she had felt in her work with different therapists over the years and the work she had been able to do with them. In trying to make sense of what created positive therapeutic connection, Dinah talks about the presence of the therapist she worked with most comfortably. She says, “There are some people who, like me, have a standoffish attitude toward people. But, just the way she carried herself made it comfortable, made me feel comfortable.” Throughout the interviews, Dinah and other participants spoke about the impact of their relationships with various therapists and the ways that these relationships affected their well-being and their
success within the therapy. Dinah’s description of this therapist as someone who made her comfortable highlights the importance of a relationship in which the individual can feel safe, open, and accepted.

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Absence of this therapeutic connection or *Lack of Therapeutic Connection* can undermine the success of the therapy. Dinah portrays one such relationship, saying:

I'm not sure why I left my second therapist. I can't remember. It could have been a combination of reasons; we weren't working well together, or she changed the hours, or I wasn't going regularly, or was not engaged with her, not connecting. She called me psychotic once and I was like, “Okay, then.” We had seen each other for a long time; we just weren't connecting. So, I stopped going to therapy for a long time.

Dinah’s account of the therapist referring to her as “psychotic,” a term that Dinah does not use for herself, represents a clear disconnect for Dinah in their therapeutic relationship. Dinah felt misunderstood and disrespected by the therapist because of her choice of words. As a result, Dinah did not feel positively enough about the relationship to continue pursuing the therapy, whatever the circumstances of the actual termination. The two relationships that Dinah describes here serve to highlight her experience of the *Differences in Therapists' Approach and Ability to Listen*. She summarizes the difference, saying, “There's a difference in approach in terms of the way they worked with clients and the way they transferred the knowledge that they had and listened.” While Dinah does not go on to describe particular examples of “the way they transferred knowledge” or “the way that they listened,” we can extrapolate from her juxtaposition of these two therapeutic relationships that one allows for a comfortable and open exchange, while the other carries the sense of restriction and judgment. These themes are summarized in Table 3.

**Dolores.** Dolores is a 64 year old, single, Caucasian woman. She was of medium height with short dark hair. She spoke in a soft, plaintive voice and often grew tearful over the course of the interview. Dolores’ movements appeared tentative and restrained, but she seemed to clearly
express her opinions and did not hesitate in describing situations in which she felt others had
been in the wrong. Like Thomas, at the end of the interview, Dolores expressed concern that she
might not have adequately answered my questions, suggesting that, despite her confidence in
conveying her experiences, Dolores felt more insecurity than she verbalized.

Dolores began receiving treatment when she was 19 years old and has received care in
inpatient and outpatient programs at various levels. She has a degree in graphic design and does
occasional freelance work. In the past, Dolores has received care from psychiatrists,
psychotherapists, and has taken part in group therapy. Dolores is currently receiving treatment
from a psychiatrist, psychotherapist, and is attending a grief support group to process the recent
death of her mother.

*My experience and impressions during the interview.* I found this interview the most
difficult to conduct for several reasons. The first was that Dolores had, for me, the most
challenging interpersonal style of all of the participants. Secondly, I had the most trouble
eliciting responses that engaged in an obvious way with my questions and prompts. While
Dolores shared a significant number of experiences, it was at times hard to relate them to the
“experience of care” rather than to experienced injustice in her life in general. Although this
information is of course incredibly relevant to the other material, I struggled not to regard it as a
tangent or distraction. It was also difficult to develop any sense of how care had changed over
time for Dolores. What she did offer to a greater degree than other participants were detailed
examples of being treated poorly, inadequately, or without respect by various support staff in her
life (particularly around education or career development). In many ways, Dolores was the most
attuned of all of the participants to instances in which she was not treated in the way she felt she
ought to have been.
My experience and impressions in the analysis. Dolores’ narrative was difficult to interpret and analyze for very different reasons than those of the other participants. Although her language was generally clear, as stated above, it was at times challenging to relate her answers to the question of “experiences of care” rather than experienced injustice in her life in general. Either the questions themselves were difficult for her to answer or she drew connections that I was unable to follow. That said, Dolores offered several, incredibly detailed accounts of having her needs not met, feeling misunderstood by her care providers, and described a certain callousness or disrespect on the part of professionals in their interactions with her. The details she offered, while they felt tedious in transcription and analysis, are of course excellent depictions of her experience.

Key themes that stood out in Dolores’ narrative. Throughout her narrative, Dolores demonstrates the fact that her experiences of care were often shaped by those providing the care. In certain instances, she found that her provider’s refusal to take into consideration the feedback that Dolores gave about her own experiences led to a deterioration of her mental health. In the theme Not Being Listened To, Dolores shares two examples of giving feedback to her mental health care provider that was ignored. During a time when Dolores was experiencing a period of steadily decreasing stability, she attempted to locate the source of her distress and share it with her provider. She explains:

I had been with this artist for a year and I was in love with him. He was an older man though and he had gotten into debts and decided he needed to go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided that's where he was gonna go, but that just really hit me badly and that's when I ended up in the hospital. When I tried to say to the doctor, “I think there's something here and I'm not
Dealing well with his leaving” and all that, he just said, “Well, there's nothing to do with that.”

Dolores felt as though her ideas had been dismissed and she had been discouraged by the provider from pursuing a line of inquiry that felt relevant in understanding her mental state. In another instance, the same provider staunchly denied Dolores’ experiences of the effects of the medications that he had prescribed. Dolores explains:

He had said I was paranoid schizophrenic and so then he was pushing all these heavy-duty so called tranquilizers and I kept telling him, . . . “I’m feeling worse and I'm feeling more anxious and more paranoid” and all this and he'd say, “No, no, no. You can't possibly, because these are supposed to treat that.”

Dolores continued to spiral out of control and eventually needed to be hospitalized, an occurrence that she directly connects to the provider’s unwillingness to take into account and respect her feedback about the effects of the medications.

As mentioned above, there is a clear thread in Dolores’ narrative of not having her needs met. Dolores describes several instances of receiving care that felt as though it missed the mark or was not provided in a form that felt helpful. These observations make up the theme Care that Didn’t Feel Helpful. Dolores offers the example of attempting to pursue Dialectical Behavior Therapy:

The first experience I had with it didn't feel really helpful to most of us in the group, because they weren't showing us how it could relate to our own life and how we could use it every day. So, I don't think I got so much out of that one.

Although both Dolores and her care providers were interested in her pursuing Dialectical Behavior Therapy, Dolores’ experience makes clear that having access to care does not
necessarily lead to receiving care that feels as though it adequately meets one’s needs. While she was provided with the therapy, the information was given in such a way that, at least at that time, Dolores felt unable to actually make use of it in her every day life.

In addition to exploring care that felt as though it had not met her needs, Dolores also speaks about falling between the cracks when she needed less support. While Dolores valued her experiences at the Clubhouse in which she was involved at an earlier point, the particular kind of support offered through the Clubhouse no longer seems to address her needs. Like many people, Dolores feels as though she falls into a middle ground where the ongoing full support of the Clubhouse services are not appropriate, but nothing exists to fill that gap at her current level of need. This was an experience shared, to some degree, by Thomas and is part of a theme of *A Lack of Continuity of Care* in Dolores’ narrative. In particular, Dolores misses the social support and organized community aspects of the Clubhouse. She acknowledges that once people have “graduated,” there is likely the expectation that they’ll “get together with those friends or whatever and do [their] own things,” but points out that this still fails to meet the need for professional support in particular. She says, “It might be a nice thing to have somebody that was a staff . . . In case you wanted to bounce certain things off of them.” While neither Dolores nor Thomas need support services on a daily basis, they both now find themselves in a position where it’s not entirely clear who they would go to in a situation of need.

Beyond falling into a sort of limbo with regard to support, Dolores’ narrative contains a theme of *Not Being Treated with Respect or Fairness* at times when she has had support services. Dolores experienced particular difficulty with vocational support services and says, “I feel that I wasn't dealt a fair option in that area." Dolores describes one particular support staff with whom she worked for some time who Dolores experienced as seeming to try purposefully
to derail Dolores’ efforts, providing her with information that was inaccurate. In addition, Dolores felt consistently disrespected in her interaction with the staff member. She shares one particular experience with this staff member that took place during a meeting between Dolores, the vocational support staff, and an educational support staff in which they were looking over some of Dolores’ required paperwork.

The vocational support staff, she's like looking all the sudden at me and with this smile and she says, “Well, now you're an artist, so what's to stop you from whiting this out and writing something different in there?” And the educational support staff said to her, “Why on earth would you say that to her? That doesn't apply at all.” And she goes, “She's never done anything that's been underhanded or not decent or honest.”

Dolores’ sense of being unfairly victimized by the vocational support staff comes through clearly in this narrative and is underlined by the response of the educational support staff. What is also made clear is the vulnerability of Dolores, as a client, in this situation. Luckily, Dolores had other support staff who were able to speak to the disconnect between the vocational support staff’s comments about Dolores and their own observations of her. One can easily imagine that someone with less outside support or less of an ability to advocate for themselves might have been derailed by similar situations.

With regard to considering the impact of others on one’s own mental health trajectory, both Dolores and Dinah speak about the ways in which they have been impacted by their families’ involvement in their care choices. For Dolores, this aspect of her narrative makes up the broad theme Family Interfering with Access to and Success of Care. The two threads within this theme can be separated into Dolores’ experience of How My Family Felt about her attempts to access care and How Family Impacts Coping. In speaking about the first theme, Dolores says:
My first attempts to find care were kind of hit or miss, because my parents were not behind me getting involved in therapy. They're from a different generation altogether and they didn't want people knowing that I was going to be in care.

Dolores’ family’s feelings about her pursuing care effectively delayed her initial attempts to seek it out. It also meant that when she did begin to seek out care, she had to explore what options were available to her on her own.

In speaking to the second theme, Dolores explains that even after accessing care, she continued to feel the impact of her family relationships on her mental health. She says:

One of the first psychiatrists that I was with for about ten years, at one point he said to me and he said it to my parents to, he said, “I get her feeling better about herself and then she comes home to the family life and she's down again and being taken down,” and he said, “that's not working to help her.”

This was made clear in Dolores’ description of providing care for her aging mother. Dolores speaks about the immense emotional impact of caring for a woman who often lashed out verbally and physically at her. When Dolores spoke to someone about the incredible stress and emotional distress she felt, questions were raised about her ability to provide care for her mother as well and about the potential of elder abuse. The experience caused Dolores significant pain, as was clear in our interview.

Despite, or perhaps because of, Dolores’ repeated experiences of being treated poorly, inadequately, or without respect, her narrative includes several instances of taking action for herself in these same situations. I have labeled this aspect of Dolores’ narrative Speaking Up for Needs and Making Decisions About Care. A prime example of this thread in Dolores’ narrative has to do with the same vocational support staff that appeared to be attempting to derail Dolores’
efforts. Dolores was able to identify this behavior as unacceptable and to take steps to seek appropriate support. She says, “After having humiliating experiences with her, I finally did switch with the help of an advocate who came in and we talked with her boss and I just switched to somebody else." Though Dolores shares this in an incredibly matter of fact way, it is, of course, sadly remarkable that she felt able and was empowered to take such action.

A more nuanced example of Dolores taking a stand with regard to her needs and desires in care comes through in her negotiations with her psychiatrist over her use of a specific medication. She says:

Now my regular psychiatrist is telling me that I really should get off of that medication, that it's been linked with Alzheimer's and that type of thing. But since my mother died I'm really not in a good place at this point. So, I had tried not using it and just using it sparingly and all that. But this past time I saw him I said I would sign something releasing him from any responsibility of anything, I said, “but I don't think I can completely do without this or having it available if I did need it or whatever.” And so he said, “Well, you don't have to sign anything, I'll just put it in your chart.”

Looking across the narratives, it is remarkable that Dolores felt able to stand firm about what it was she needed, even though it was in direct contradiction of her psychiatrist’s opinion. She was able to take his feedback into consideration and try the adjustment, but when dissatisfied with the results, she was clear and unmoving about her own needs. This, of course, likely reflects some of the changes in psychiatry that all of the participants spoke to, but also reflects Dolores’ unique ability to prioritize her own interpretation and experience of a situation even in the face of resistance. These themes are summarized in Table 4.
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<td>Speaking Up for Needs and Making Decisions About Care</td>
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<td>Being a Leader</td>
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<td>Speaking Out</td>
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<td>Not Trusting Self</td>
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<td>Feeling Anxious about Capabilities</td>
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<td>Not Being Offered a Chance</td>
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### Themes

**Points of convergence in the narratives.** The narratives of the four participants were, in many ways, incredibly different. While all of the participants shared a history of hospitalization, working with a psychiatrist, taking psychiatric medication, and working with a psychotherapist, the details of these experiences and how they felt about them were quite varied. As discussed in the Exploration of the Interview and Analysis Process and Key Themes in Each Narrative, each
participant also focused on very different aspects of their experience. It is somewhat difficult to identify the similarities across the narratives. However, as shown in Table 5, there were four points of convergence across all four narratives. These four points of convergence were around themes having to do with negative experiences in treatment, themes having to do with taking psychiatric medication, themes having to do with the varied forms of support available to participants, and themes around changes in the perceived respect for their input and growing involvement of clients in decisions about their own care. These themes are summarized in Table 5.

*Treatment that was unsupportive, unwarranted, dehumanizing, or traumatic.*

*Thomas: The hospital was a dark time.* Thomas speaks least about this aspect of his experience. It is, of course, possible that he had fewer experiences that he would have identified in this category. Another possibility is that Thomas’ understanding of treatment differs slightly from that of the other participants. Thomas seems more willing to assume that the motives behind the treatment were appropriate, even when he disliked or disagreed with it. The only indication Thomas gives that he felt ambivalent about the treatment he received at times was in talking about his experience in the partial hospitalization program. He says, “It was kind of a dark time for me, the partial hospital. It was rough. We did chores there, which I guess were probably designed to help you in your recovery, but it was difficult.” Thomas expresses a willingness to assume that the experience that was difficult for him was nonetheless designed to support his recovery. This might be a learned reframing of a negative experience, relevant to Dinah’s assertion that there is a certain script that is seen as acceptable within mental health care that clients learn in order to move through the system more easily. Alternatively, Thomas may be more willing to suspend his own beliefs and desires in deference to the imagined expertise of
those providing his care.

<table>
<thead>
<tr>
<th>Common Theme</th>
<th>Thomas</th>
<th>Leah</th>
<th>Dinah</th>
<th>Dolores</th>
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<tr>
<td>Treatment that was Unsupportive, Unwarranted,</td>
<td>The Hospital was a Dark Time</td>
<td>No Support, Just Horror</td>
<td>Treatment that is Unwarranted, Dehumanizing, and Traumatic</td>
<td>Care that Made it Worse</td>
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<td>Dehumanizing, or Traumatic</td>
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<tr>
<td>Support in Many Forms</td>
<td>Support in the Past</td>
<td>Sources of Support</td>
<td>Using Social Supports</td>
<td>Getting Support</td>
</tr>
<tr>
<td>Being Respected, Listened to, and Involved</td>
<td>Being Listened To</td>
<td>Being Respected and Giving Input</td>
<td></td>
<td>The Clubhouse Offers Community</td>
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<tr>
<td>The Impact and Effects of Choosing to Take</td>
<td>Independence and Functioning</td>
<td>A Zombie</td>
<td>The Impact of Choosing to Take Medication</td>
<td>The Effects of Medication</td>
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<td>Medication</td>
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Leah: No support, just horror. Leah’s reflections on this theme are less centered on the care provided and more focused on the environment in which the care was received and, in many
ways, actually seems to demonstrate an absence of support and care during her hospitalizations. In contextualizing the situation in which Leah found herself, she says:

So here I was, in this ancient city hospital. I'm eight months pregnant on a psych unit.

This was in the 1960s, so there was this long, dark hallway. There were nuns who were patients there, sitting on the edges of their bed. And here I am, knowing I'm going to lose my child . . . So they put me in this hellhole. I was hysterical. All I did was cry. It was just god-awful.

Leah was hospitalized following a suicide threat she made when she realized that, as a pregnant, unwed, teenager, she would receive no support and was unlikely to be able to keep the child. In our interview, Leah says that she believes the threat was made out of desperation and did not reflect an actual suicidal ideation. Regardless, the result of the threat was hospitalization, rather than the provision of support that might have made her situation feel more tenable. Leah provides a vivid description of the environment within the hospital:

It was so institutionalized. It was horrific. The beds were so close. People were hallucinating and crying and sobbing all night. We wandered around the day room, you know, the stereotypical wandering around the day room. People could smoke, so there's a little thing on the wall so they could light their cigarettes. There's no place to sit. There's one or two couches that everybody's vying for. I got shock treatments with no freaking anesthesia. There was one person, or perhaps two, that were kind. Everybody else was just horrible.

The hospital that Leah describes is the stuff of movies; a landscape that she portrays with such feeling that it is easy to imagine the horror and fear of it. While Leah’s description is of a world that may no longer exist in that form, it nonetheless contextualizes the environment in which a
generation of mental health consumers received care. As mentioned above, Leah’s recollection of her initial experience in hospitalization is one that is notable for its absence of active care, rather than of care that was itself problematic. She makes this explicit, saying:

I don't remember any interaction with the people who worked there. All I did was sit in my room. I mean, I suppose I got food and stuff, but I don't remember that part. I just remember the horror of it.

As someone whose very hospitalization was the result of a perceived lack of support and care, it is painful to consider the isolation and hopelessness in Leah’s description of her time there.

Dinah: Treatment that is unwarranted, dehumanizing, and traumatic. In contrast with Leah, Dinah’s narrative reflects an aspect of this theme that directly speaks to choices made by those “providing care” for her during her hospitalization. Unlike Thomas, Dinah expresses no ambivalence about the therapeutic potential of the actions taken towards her. Dinah describes one of several experiences of restraint that she has undergone over the course of her past hospitalizations. Dinah begins her description with an unequivocal statement that the restraint was unnecessary and uncalled for:

When I say that I didn't do anything to warrant those restraints, I mean that. Who does anything to warrant that? . . . I wasn't, like, escalated. People restrained me in order to get me to take medication or because . . . I had gone into a patient's room in a distressed moment . . . I went into the patient's room and I rubbed his head and I called him my brother’s name and that was it. But evidently, I didn't have on any clothes at the time . . . But I wasn't a danger to the patient and I didn't do anything that was violent . . . it didn't warrant eight people throwing me down on a gurney and restraining me for a night.

While Dinah is open in describing her behavior as perhaps unsettling, she makes the distinction
between the unsettling nature of her behavior and the actual danger of her behaviors. Implied in her description is a recognition that her behavior perhaps warranted some intervention, or, at the very least, might have caused a disruption for those around her. However, as she points out, it would be difficult to argue that it merited restraint by eight people over several hours. But Dinah goes beyond arguing that her own behavior in this situation did not merit the use of restraint. She is clear in her position that restraint, as she experienced it, is an unacceptable option. Dinah says:

I like to think I'm a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. I think none of us, there's not a single solitary soul, that I feel deserves to be placed in four-point restraint.

While it’s unclear whether Dinah is arguing that there is no situation in which four point restraints should be used, the argument that no one “deserves” the experience of being put in four point restraint is clear. Many hospitals have worked, in recent years, to ensure that restraint is used only in situations in which someone is in danger and that the restraint is used for the briefest period of time possible, in recognition that the experience is traumatic even at its best. Dinah shares, from her own experience, a compelling description of the effects of being restrained:

When I was a child, I was molested and no one listened to me . . . So, when I was restrained, it felt like my body wasn't my own and no one was available to hear me or that they didn't care how I felt. It felt punitive, not like it was healthcare.

Dinah’s history of sexual abuse meant that the experience of restraint amounted to a re-traumatization. Her identification of the experience as punitive is a telling indicator that the choice may have been made to punish her for creating an unsettling situation rather than to keep Dinah and those around her safe.
Dolores: Care that made it worse. Dolores’ narrative, unlike those of the other three participants, touches on her belief that treatment she received actually caused the deterioration of her mental health or at least negatively impacted her stability. In her narrative, she describes the aspects of the care she received that she identifies as having negatively affected her:

I think, looking back on it, that working with [the psychoanalytic psychiatrist] triggered my posttraumatic stress, because the psychiatrist was an older man and my grandfather had been an older man . . . But I just started getting worse and hearing voices and I started hallucinating things and I was in and out of hospitals. So, I wasn't doing well at all. His type of therapy, where you don't even say hello to the person, that was not for me at all. It was just so impersonal . . . sometimes I couldn't talk and I would just be looking at the floor and there would be silence for almost 50 minutes and so that was not really conducive to me speaking or feeling comfortable or anything like that.

Dolores does not necessarily suggest that the care she received was in and of itself bad, but rather that it played upon her particular areas of sensitivity in ways that were detrimental to her stability. The clinician’s rigid adherence to an approach that appeared to antagonize Dolores’ vulnerabilities and failed to provide her with the holding space that she needed at the time does, of course, suggest a failure to provide adequate or appropriate care.

The impact and effects of choosing to take medication. Themes regarding the impact and effects of medication, though they looked very different for each participant, were present in all four narratives. Negative side effects along with the risks of being excessively or inappropriately medicated are often a concern of individuals who take psychiatric medication. Leah speaks to this concern in her narrative, in the theme A Zombie. In comparing her relationship with her current psychiatrist with her experiences while under the care of other psychiatrists, she says,
“Before, I was a frikking over-medicated zombie. I was obese. When I started volunteering at the advocacy organization, I was a zombie. I could barely speak because my mouth was dry, dry, dry.” Leah’s description points to her experience of medication interfering with or impeding her functioning, an experience echoed in Thomas’ narrative. In the theme Independence and Functioning, Thomas talks about the impact of being on a medication with significant side effects. He says:

The thing that was the most helpful for me was when they came out with the medication Zyprexa. That was kind of a turning point for me, because before that the medications that I took had so many side effects that I wasn't really doing very well, mentally.

Like Leah, Thomas describes the side effects of his medication as a handicap, which, while it may address his mental health issues, limits his quality of life in significant ways. In his narrative, Thomas identifies being able to begin taking a medication with fewer side effects with his beginning to function at a level that enabled him to develop more independence.

Dolores also identifies finding the right medication as an important aspect of her well-being. In her narrative, she speaks about the Effects of Medication and having to make a difficult decision to continue taking a medication that her psychiatrist has encouraged her to discontinue. Dolores explains, “The medication I'm talking about, Lorazepam or Ativan, seems to put me in a less depressed mood and to make me want to live.” In making the decision to continue taking the medication, Dolores has to weigh her psychiatrist’s warnings about long-term negative effects she may experience from continuing the medication against her certainty that she will have no quality of life in the present if she discontinues it. These are the kind of high stakes that mental health consumers routinely face when they are making decisions about whether or not to take medication and there is often significant ambivalence about these decisions. The ambivalence in
clearly illustrated in Dinah’s narrative under the theme *The Impact of Choosing to Take Medication*. As explored previously, Dinah has the most explicitly ambivalent relationship with medication of all of the participants. Dinah describes medication as a tool she has had to use because those around her require it, rather than because it is the choice that feels appropriate to her. Dinah lays out her ambivalence, saying:

> Really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years.

While she does not say what the detrimental impact of the medications have been, one can easily imagine, based on Thomas and Leah’s descriptions, what Dinah’s experiences with medication may have been like and how it might have affected her quality of life. Neither Dinah nor Dolores ever experienced a significant reduction in their symptoms or distress through the routine use of medication, a fact that one can imagine makes it much harder to choose to take medication despite the significant side effects.

**Support in many forms.** Another point of convergence in the narratives was around the theme of support. Each of the participants identified having received various kinds of support at some point during their treatment. What this support looked like varied widely between the participants, as did whom they received it from and whether they still received it.

*Thomas: Support in the past.* For Thomas, his experiences of active support primarily occurred earlier in his process of recovery. It was not clear whether this reflects a change in the system or whether this is more a reflection of Thomas’ level of need and his increasing ability to do without such support. Much of Thomas’ narrative centers on the tension between his felt lack of this kind of support and his pride in the fact that he no longer needs the same supports he
formerly had. In describing the kind of support that he had previously received, Thomas says, "The case manager I had in the past set me up with my entitlements and would make recommendations for services, like a good dentist that took Medicaid." This suggests a kind of practical support in navigating systems and seeking out resources. Thomas speaks in passing about the other services he received around the same time, such as seeing a psychotherapist, but this practical support from his case manager seems to be what Thomas recalls as being most helpful.

**Leah: Sources of support.** In her narrative, Leah identifies three different sources of support that she has experienced over the years. The first of these was the support that she received from the mental health care providers with whom she worked. Leah reflects on her earliest experience of care, saying, "When I was 14, my mother finally picked up that something was wrong and linked me with a psychiatrist. The psychiatrist was really my only friend." One could argue that the support in this situation was provided both by Leah’s mother, in recognizing her daughter’s need for additional resources, and the psychiatrist who provided the care. While Leah has had significant traumatic experiences at the hands of mental health care providers, she has also continued to have positive and supportive experiences of care. At the time of her sexual abuse by a psychiatrist, Leah was also in a supportive psychotherapy that aided her in handling her experience with the psychiatrist. Leah explains, "I did have a therapist at the time, thank God almighty it was a woman, and she knew the psychiatrist. She supported me.” In her description of that time in her life and the turmoil she underwent in trying to decide what to do about the psychiatrist’s actions, Leah speaks about her extreme distress and uncertainty. One can imagine that the therapist’s support might have been an important factor in her feeling able to choose the course she did.
Another area of support that Leah identifies is the local mental health advocacy organization where she currently works. Through both the physical and emotional stressors that Leah has experienced over the past several years, her colleagues and the organization itself have supported and accommodated her. Leah describes the organization’s reaction to her recent surgeries:

I've had four joint replacements and I was having terrible pain after the most recent knee replacement. I had very good support at work; they allowed me to work from home when I got better enough and allowed me to adapt my schedule.

The organization has been flexible and adapted to Leah’s needs in order to allow her to continue working through an incredibly difficult time. When Leah was dealing with the sexual advances of her psychiatrist, the organization was also made aware of the situation and provided support to Leah in the aftermath of that experience.

The last area of support that Leah mentions is her romantic partner. Although Leah was not the only participant to have a partner, Leah was the only participant who explicitly identified their partner as a major support during the interviews. In speaking about the continuing emotional struggle with the trauma she has experienced over the course of her life, Leah describes her partner as an important sounding board for her decision to seek psychotherapy again.

I said to my partner, who's very low-keyed about the whole thing, I said, “Honey, do you think I should go see somebody?” He'd never said yes before, but this time he said, “Yeah, I think so.” He's wonderful.

Leah’s ability to rely on the judgment and feedback of her partner is important. The other participants who spoke about the feedback given by family members and loved ones tended to
identify a sense that the advice offered typically missed the mark or was in conflict with their
own sense of what they should be doing.

*Dinah: Using social supports.* While Dinah speaks throughout her narrative about different
kinds of support she has received over the years, particularly from the therapists she has worked
with, she also talked about beginning to turn more to her friends and social community for
support. In navigating the choice of whether or not to pursue individual therapy at this time,
Dinah explores her own use of therapy as well as the ways she now fills those gaps with her
friendships. She says:

I know that there are times in my life when I do wish I had someone to talk to like that.
But really, I was probably under utilizing the outpatient therapy. At this point, I consult
my friends if I want to talk about something.

This choice is an important indicator of the social supports that are available to Dinah, as well as
being what she feels she needs at the moment. It also seems to represent the shifts in the level of
support that Dinah has needed over the course of her recovery. As is explored elsewhere, Dinah
describes the changes in the ways that her therapists worked with her over time. The intensive,
community based therapy eventually became unnecessary, at which point she moved to a more
typical structured therapy. Dinah is now at the point where even that structured therapy may be
less necessary and may give way to the emotional support she receives from her friendships and
community.

*Dolores.* In Dolores’ narrative, there were two different themes that connected to the idea
of getting or receiving support. The first of these themes was *Getting Support* and it touched on
the ways in which Dolores accesses the support she feels she needs now. Dolores describes one
of the important current supports in her life as the resident advisor in her subsidized housing. She
I live in subsidized housing. It's mostly for elderly, but there are a few of us that are younger and disabled or whatever. And the resident advisor is a very kind person and so I feel less alone because I can go to her about different things that come up, financially or just housekeeping type things or whatever.

In some respects, Dolores’ description of the kind of support this individual is able to offer is reminiscent of the support that Thomas previously received from his case manager. This is a kind of everyday, practical support that gives Dolores a sense of safety. The resident advisor is someone that Dolores feels she can rely on.

The other theme within Dolores’ narrative that related to the idea of support was *The Clubhouse Offers Community*. This theme centered on the kinds of support available through the Clubhouse, but also spoke to the sense of social community that Dolores feels that she and others lack without the Clubhouse. Dolores says:

I think the Clubhouse was helpful to me and I think clubhouses are helpful . . . we used to do a lot of different things that I probably wouldn't have gotten to do and at that time you only had to pay five dollars and what they did was . . . put that into a pool of money and so they would pay the rest, like if we went to a movie or something like that. So they made it very affordable and they don't do that now. It's one major outing that they do and they don't do the weekends like we used to do. Because a lot of people, I think, on the weekends can feel like at a loss.

While Dolores is partly describing the sense of social community that the Clubhouse helped to create when she was there, she is also, of course, pointing out the changes within the Clubhouse itself. Like Thomas’ exploration of the changes in both the availability of and his need of the
support of a case manager, Dolores too speaks about feeling as though she no longer requires the level of support that she received from the Clubhouse. However, Dolores speaks more explicitly than Thomas about feeling as though she falls into a category of mental health consumers for whom there are inadequate services.

**Being respected, listened to, and involved.** The last point of convergence among all four participants was around the theme of being involved in their treatment choices and having their opinions and desires respected by their mental health care providers. Across all four participants, there was a recognition that this had not always been the case, but for all them there was an increased sense that this should be the expectation in working with a provider.

**Thomas: Being listened to.** One of the few explicitly negative aspects of his experience in treatment that Thomas shares is having his feedback about the side effects he was experiencing ignored. This is juxtaposed with Thomas’ description of his relationship with his current prescribing clinician. Thomas says, "The psychiatric nurse I see now listens very carefully to what I say, and luckily the medication seems to agree with me." Thomas is now able to feel confident about the fact that not only will he be heard, but that he is listened to “very carefully.” This suggests a new sense that his feedback is not only welcome but is also vitality important.

**Leah: Being respected and giving input.** While Leah does not speak in much detail about times she has felt that her input was not welcomed or valued, this is hinted at in her description of previously having been heavily overmedicated. However, Leah is explicit in stating the difference between her past experiences of psychiatric care and those that are more recent. She says:

I’ve been in treatment, on and off, since I was 14. The care that I receive now compared to the care I've received in the past is like day and night. The kindness and letting me
have my own input. I'm still on a little bit of medication, but I discuss it with the psychiatrist and she says, “Well, what do you think?” We talk and she let's me give input. In addition to the wildly different experience of being asked to contribute to decision-making about the medications she takes, Leah also describes a relationship with her psychiatrist that is one of mutual respect. She says, “We just get along well and I respect her and she respects me. She let's me guide how things are going to go.” One can imagine how different this level of involvement and agency might be from psychiatric care that Leah received previously.

*Dinah: Client involvement in treatment decisions and change.* Perhaps because Dinah’s relationship with medication is the most explicitly ambivalent of all of the participants, the themes within her narrative that touch on the topics of involvement and respect in treatment decisions are somewhat different from those of the other participants. It is possible that Dinah’s description of the changes in her psychiatrist’s perception of her over the years is an implicit statement that she has had a similar experience to the other participants, but she does not clearly say that this is the case. However, although Dinah does not clearly state that she has felt a change in how she is involved in treatment decisions with regard to medication over the years, she does speak about the role that she believes clients must have in making sure that the changes in care do take place.

If we don't, as clients, insist that we're a part of it and that the conversation takes place, I think there's a risk that it will continue at the status quo. It's almost like we have to [say] . . . "Are you gonna ask me what my goals are in different areas of my life? Do I have financial goals; do I wanna own a house or get a different apartment? Do I want to have social relationships that are rewarding?" . . . And I think we have to insist, as clients. We have to give them the questions when they don't have them.
Dinah acknowledges that even she, knowing that she should be asked these questions, doesn’t always insist that they be asked. Dinah makes clear that she believes it is in part this complaisance in mental health consumers that allows clinicians and care providers to continue in the “status quo.”

_Dolores: Speaking up for needs and making decisions about care._ Dolores does not identify feeling as though her opinion and perspective are more accepted or valued by her care providers, but she does speak about an instance in which she acted as a strong advocate for what she wanted to do and, while she does not explicitly label this aspect of her experience, her desire was acknowledged and accepted by the clinician with whom she works. Dolores shares a recent experience in which her psychiatrist pushed her to change her medications. Dolores felt strongly about continuing to stay on the medication and made this clear to the clinician:

> Now my regular psychiatrist is telling me that I really should get off of that medication, that it's been linked with Alzheimer's and that type of thing. But since my mother died I'm really not in a good place at this point. So, I had tried not using it and just using it sparingly and all that. But this past time I saw him I said I would sign something releasing him from any responsibility of anything, I said, but I don't think I can completely do without this or having it available if I did need it or whatever. And so he said, “Well, you don't have to sign anything, I'll just put it in your chart.”

Dolores’ unequivocal statement of her position and her insistence that the clinician accommodate her needs this reflects Dolores’ strong self-advocacy and agentic decision making which was, in the end, respected by the psychiatrist.

 Themes across three participants.

*Not being respected, listened to, and feeling powerless.* This was a theme that repeated
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<th>Common Theme</th>
<th>Thomas</th>
<th>Leah</th>
<th>Dinah</th>
<th>Dolores</th>
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<tr>
<td>Not Being Respected,</td>
<td>Being Made to Feel Small and Being Disregarded</td>
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<td>Desires About Medication Aren’t Respected</td>
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<td>Disrespecting Clients</td>
<td>Not Being Offered a Chance</td>
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<td>Feeling Unable to Advocate for Self</td>
<td>Not Being Listened To</td>
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<td>Finding Help</td>
<td>Choosing Not to be in Therapy</td>
<td>Choosing what Care is Important at Different Times</td>
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<td>Speaking Up for Needs and Making Decisions About Care</td>
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<td>Independence and Functioning</td>
<td>Beginning to Thrive Again</td>
<td>My Process of Recovery</td>
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<td>Things Turned Around</td>
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in the narratives of Thomas, Dinah, and Dolores. All three spoke about interactions with providers around issues of medication in which they felt as though their perspective, desires, and input weren’t acknowledged. As mentioned previously, Dinah had the most explicitly ambivalent experience with and perspectives on medication. As such, she has frequently felt as though care providers she came into contact with did not respect her desire not to pursue medication. In the theme *Desires About Medication Aren’t Respected*, Dinah speaks about her frustration with this dynamic as it occurred in one of her experiences of hospitalization. Dinah says:

The doctor at the hospital, she wanted me to take medicine and so that was her goal, for me to take medicine in order to get out. I mean, she didn't say, “Okay, well, let's look at some alternative ways for you to heal.” For her, medication was the answer. And talk about cultural competency and respecting somebody's desires not to take a pill, not to take a chemical!

Dinah’s experience was that the psychiatrist’s beliefs and desires trumped Dinah’s own. She felt that her perspective was devalued and she was not made a partner in finding the path that best suited her. Throughout all of her hospitalizations, Dinah describes feeling coerced into taking medication despite her clearly stated desires to the contrary.

Of course, even after a client makes the choice to take medication, this can still feel disempowering and be a source of conflict. This is illustrated in Thomas’ account of the psychiatrist he worked with in the partial hospital program in the theme *Being Made to Feel Small and Being Disregarded*. He says:

The psychiatrist at the partial hospital program came from the prison system; he was very stern and he had a bad temper. So, it was hard working with him . . . they put me on some medications that didn't agree with me. When I asked to be changed to something else,
they didn't listen to what I said. They disregarded my input and so I struggled for a long time with side effects from the medication.

In comparison to Thomas’ experience with his current prescribing clinician, where he feels “listened to,” Thomas’ input was ignored. While he does not state this explicitly, Thomas’ narrative also suggests a feeling of being at the mercy, so to speak, of this psychiatrist.

Dolores shares a similar experience of Not Being Listened To in her narrative. She describes a particular mental health care provider that she worked with, who dismissed her insights about her experience and ignored or refuted her feedback. Dolores explains one instance in which this happened:

I had been with this artist for a year and I was in love with him. He was an older man though and he had gotten into debts and decided he needed to go back to Alaska, ‘cus at that time the pipeline was big and he could make big money. And so he decided that's where he was gonna go, but that just really hit me badly and that's when I ended up in the hospital. When I tried to say to the doctor, “I think there's something here and I'm not dealing well with his leaving” and all that, he just said, “Well, there's nothing to do with that.”

Dolores’ sense of her own experience and distress was ignored. Perhaps as a result of this, Dolores’ emotional and mental stability deteriorated. In addition to having her perception discounted, Dolores’ feedback about the effects of the medication also went unheeded.

At that point he had said I was paranoid schizophrenic and so then he was pushing all these heavy-duty so called tranquilizers and I kept telling him, . . . “I’m feeling worse and I'm feeling more anxious and more paranoid” and all this and he'd say, “No, no, no. You can't possibly, because these are supposed to treat that.”
Dolores’ understanding of her own mental and emotional state and her physical and emotional experience were rejected and denied, overridden by the psychiatrist’s sense of the rightness of his assessment.

Beyond questions of medication and treatment, Dinah, Thomas, and Dolores also all had experiences of being treated in ways that felt disrespectful or being treated as though their diagnosis diminished their worth in some way. Thomas talks about the effect other staff and care providers have had on him in comparing the two different directors he has worked with at the Clubhouse. He describes the personality of the first director and the effect that her behavior and actions had on his sense of himself. Thomas says:

The personality of the first director was more dictatorial. She was more emotional, sort of hot tempered, and she could get very angry. She had a way of making me very uncomfortable when I did something wrong. She would raise her voice and she had an angry tone. She just had a way of making me feel small I guess you could say.

Thomas’ portrayal of the director hints at the power differential he felt in interacting with her. The words he uses suggest that the director made him feel not just like a work subordinate but also as though he is less capable and of less importance.

Dinah also speaks about interactions with providers that have felt indifferent (Disrespecting Clients). She describes a previous therapist who referred to Dinah as “psychotic.” This is not a label that Dinah herself uses and so she found the therapist’s use of it in this case offensive. Dinah explains, "That is disrespectful, I think, to call someone psychotic when that's not a word I use to refer to myself under any circumstance." Dinah argues that to use a term for someone that they would not use themselves is an act of disrespect, a direct violation of their understanding of themselves.
Beyond these subtler experiences of disregard, Dolores describes a particular staff member routinely attempting to sabotage or hinder Dolores’ progress in pursuing her education and work (Not Being Treated with Respect or Fairness). When someone at the school Dolores was attending changed information on her forms, the vocational support staff accused Dolores of forging the information.

And so when we get into the meeting with the vocational support staff, she's like looking all the sudden at me and with this smile and she says, “Well, now you're an artist, so what's to stop you from whiting this out and writing something different in there?” And the educational support staff said to her, “Why on earth would you say that to her? That doesn't apply at all . . . She's never done anything that's been underhanded or not decent or honest.”

While this is an extreme example, it illustrates Dolores’ sense that she is often treated discourteously by the individuals she has come into contact with in pursuing care, educational support, or employment. The example highlights the degree to which mental health consumers can be at the mercy of those providing them with support and care.

In the theme Not Trusting Self, Dolores explores how the repeated denial of her experience led her to question her own understanding of herself and her sense that she had the right to advocate for care that felt better. She describes the feeling, saying, "I was just so sick and then I felt like, well, if I give up on this then I am just kinda wimping out and maybe I need to hear what he's saying or need to do this.” The repeated undermining of Dolores’ experience made it difficult for her to value and attend to her own sense of what she needed. Dinah speaks about this in the theme Feeling Unable to Advocate for Self. Reflecting on Dinah’s observation that it is in part the client’s responsibility to ensure that the status quo in mental healthcare is not
maintained, she speaks to why this advocacy is sometimes difficult to do:

One of the things that I don't do is self-advocate very well. I teach it to other people. You know, it's one thing to teach it, it's another thing to practice it. But, that's the kind of advocacy we teach: self-systems and legislative . . . You have to speak up for yourself, I know, but there's something that prevents me from speaking up and it's probably because stuff like that hurt me deeply, like being called a name, hurts me so deep, like to my core, that I don't always have the words to combat it.

Even as a highly educated professional in the field, Dinah shares that she often finds it difficult to speak up in situations that require self-advocacy. She points back to prior traumas and to incidents such as her therapist calling her “psychotic” to elucidate the difficulty of advocating for oneself in the face of multiple experiences that make one feel powerless or deficient. These themes are summarized in Table 6.

**Lack of support or lack of therapeutic connection.** While Thomas, Dinah, and Dolores’ narratives all contain aspects of this theme, there are two different threads within the theme. The first one relates to a lack of support in services the participant accesses. In Thomas’ narrative, the theme *Experiencing a Lack of Support* explores the differences between the services that are available to him now and services that were previously available to him. Thomas says, "I used to have a therapist, but now there isn't really anybody I could talk to in depth about personal problems. I stopped seeing the therapist about 15 years ago." While Thomas generally seems accepting of and comfortable with the changes to the level of supports available to him, he recognizes that there is no clear person for him to turn to in a time of need at this point in his recovery.

The theme of *Work Readiness Rather Than Emotional Support* in Thomas’ narrative is
closely related to the previous theme in the sense that both the nature and level of the support available to Thomas has changed. In speaking about the way that the staff at the Clubhouse interact with him, Thomas observes that:

I do feel somewhat limited by my disability. I'd prefer that maybe the staff not be so judgmental or critical when I make a mistake. But, at the same time, I think they're trying to create an environment where you experience what you would in the community, if you had a job out there.

He describes the staff at the Clubhouse holding him to a high standard, something in which he takes great pride. However, there is also a sense of pain around times that he hasn’t lived up to these standards. While Thomas can rationalize that this is an attempt to foster work readiness in preparing him for a working environment outside of the Clubhouse community, these responses to his mistakes leave him without emotional support in handling the stressors and difficulties of the job.

Like Thomas, Dolores’ narrative points to places where support has fallen away over the years (Lack of Continuity of Care). Although Dolores appreciated her involvement in the Clubhouse earlier in her recovery, at this point it no longer feels like the appropriate setting for her to receive support. And yet, there are still needs that Dolores has which the Clubhouse had previously met that now go unfilled.

It's too bad they don't have some kind of a graduation group. But I guess they expect that you'll get together with those friends or whatever and do your own things. But it might be a nice thing to have somebody that was a staff too, in case you wanted to bounce certain things off of them and stuff.

While there are many elements of the Clubhouse’s services that are no longer necessary for
Dolores, the social, emotional, and practical everyday support that it previously offered are now lacking for her. She speaks here to a desire for a continuum of services and support that are so rarely available for people further along in their recovery process.

The second thematic thread within the participants’ narratives is that of care that is in place but feels as though it isn’t adequately meeting their needs. Dolores had several experiences of care that fell within the theme of Care that Didn’t Feel Helpful. One of the examples she shares was trying Dialectical Behavior Therapy and finding that there was a lack of follow through in making sure that clients were able to apply what they were learning outside of the group.

The first experience I had with [Dialectical Behavior Therapy] didn't feel really helpful to most of us in the group, because they weren't showing us how it could relate to our own life and how we could use it every day. So, I don't think I got so much out of that one. These treatment or care experiences are presented as missed opportunities in which something beneficial might have transpired, but didn’t because it was not provided in a way that was useful or applicable for those receiving the care.

In her narrative, Dinah describes a few of the different therapeutic relationships that she has had, some incredibly positive. Dinah’s first experience in therapy was one that felt very supportive and in which she found a strong therapeutic connection. Dinah contrasts that experience with the following therapy in which she was engaged. When she explores the reasons behind her work ending with this second therapist, Dinah speaks to a broad sense of there being a lack of connection in the therapy (Lack of Therapeutic Connection). She says:

I'm not sure why I left my second therapist. I can't remember. It could have been a combination of reasons; we weren't working well together, or she changed the hours, or I wasn't going regularly, or was not engaged with her, not connecting. She called me
psychotic once . . . We had seen each other for a long time, we just weren't connecting.

So, I stopped going to therapy for a long time.

Dinah lays out a number of factors that might be behind this lack of connection, perhaps most notably the therapist’s lack of respect for the language that Dinah chooses to use and identify with in regard to her mental illness.

Dolores also speaks about the theme *Lack of Connection with Therapist*, which primarily takes the form of dissatisfaction with her current therapist, whose responses and perspective seem out of sync with what she herself is feeling and wanting. Dolores says:

I dunno what's going on with this therapist, unless it's just that I'm more depressed and I'm not finding levity in anything, but some of the things that he's finding funny, I'm just not finding funny. I guess he's maybe just nervously laughing about something.

Dolores speaks about here current therapy in which she feels unmet and unsupported, with sessions often ending in her feeling more anxious than when they began. At one point during the interview, Dolores comments that although she still feels that there is significant work for her to do in coming to terms with her trauma history, she is not in a therapeutic relationship in which she feels able to do that work. These themes are summarized in Table 6.

*Making choices about care.* Leah, Dinah, an Dolor es all speak about recent choices they have made about care and the factors that they considered in making these decisions. In the interview, Dinah talks about not being in therapy after many years of having received treatment (*Choosing Not to be in Therapy*). She says, "It's something that I may pursue again, but I spent a long time in therapy already. So, for the moment I just see a psychiatrist for medication management." While Dinah’s statement is hardly remarkable at face value, the implicit meaning here is important. Dinah is able to make agentic choices about when, how, and with whom she
enters into treatment. In addition, as discussed previously, Dinah has access to enough support in her social community that it currently meets her needs for emotional support.

Like Dinah, in the theme Choosing What Care is Important at Different Times, Dolores describes the supports and treatments she is currently utilizing and explains how these choices have changed to accommodate her needs.

I have a therapist. I also have a psychiatrist who I only see every couple of months for medication. I was in group therapy also, but after I lost my mother in July I started a grief support group instead.

While similarly unremarkable, Dolores negotiating what supports will serve her best at different times is an illustration of how far she has come from her first experiences in mental health treatment in which she lacked certainty or self confidence when her judgment diverged from that of her provider.

In what is perhaps a higher stakes example of this theme, Leah talks about Finding Help following her traumatic experience with the psychiatrist she had been receiving care from for many years. In her narrative, Leah identifies the strong feelings she had about continuing to receive care in the community in which she lives. She says, “I didn't want anybody from around here. I got out of Dodge, as it were, and got linked with the psychiatrist I see now, out of town.” Leah had a strong sense of what it was she needed and wanted and she took action to seek out a solution that would meet her needs. These themes are summarized in Table 6.

The process of recovery. In Thomas, Dinah, and Leah’s narratives, the process of recovery is described as gradual but measurable through the improvements that the participants experienced in their lives. For Thomas and Leah, this is illustrated in their ability to begin moving forward again in their professional and personal lives. In the theme Things Turned
Around, Leah talks about beginning to build a life after the traumas of her early adulthood. She describes this time, saying, “I ended up getting married and things turned around. Everything was great. I was happy. I still didn't have my first child, my daughter, but I had my first son and then my third child.” This sense of progress and creating a family suggests an involvement with life that Leah hadn’t found possible directly following her early hospitalizations. Beyond just surviving, Leah highlights the importance of feeling as though one is thriving in the theme Beginning to Thrive Again. Leah gives us a general idea of what this has meant for her when she says, “I was beginning to thrive when I got hired at a local mental health advocacy organization.” Thriving then implies not just emotional and mental stability, but growth and development of one’s professional self as well as one’s personal self. This same feeling is echoed in Thomas’ narrative through the theme Independence and Functioning. Thomas describes beginning his training as a chef after a particularly difficult time in his life. He says:

I went back to school and got a culinary arts certificate and got involved with cooking and I found that the work was not only financially lucrative, but it also helped me in terms of my symptoms, keeping busy, and not thinking about my problems so much. Thomas discovered that working as a chef, a job that challenges and satisfies him, enabled his recovery further. While he identifies this as being in large part because it keeps him “busy” and helps him “not to think about his problems,” one can easily imagine that the sense of skill, accomplishment, and value is an equally important factor in Thomas’ successes.

Another way in which the process of recovery is measured in these three narratives is through the changes in the kind of mental health care and support that the participants required. In the theme, My Process of Recovery, Dinah illustrates these shifts in her description of her relationship with one of her first therapists. She says:
She saw me through and worked through some of the darkest days. Like, early in recovery. I mean, I wouldn't even consider myself in recovery at the time she was seeing me. I was paranoid, I had a very low self-esteem just because I was coping with a mental health diagnosis in the first place and she lived that through with me and saw me progress to the point where she said, “I cannot keep you as a client anymore. You have to move on from here. You're not in crisis at this point.”

Although this therapeutic relationship was an important one for Dinah and one she mourned the loss of, there is also significant pride in the positive changes that took place in her own life that meant that she was no longer an appropriate client for the level of care that the therapist provided. This same idea is concisely presented in Leah’s description of her improvement following her family’s move back to Connecticut after her father was hospitalized. She says, “After we moved in with my aunt and uncle, I wasn't in treatment. I was doing pretty darn well.”

These themes are summarized in Table 6.

**Themes across two participants.**

**The impact and involvement of family.** This was a reoccurring theme in Dinah and Dolores’ narratives. For both participants, family has had a significant impact on their treatment choices and their general well being. In part, this is due to an essential mismatch in their own desires for care and those of their family. In her narrative, Dolores explores how her family’s perspective on mental illness and mental healthcare impacted her getting connected with care when she first attempted to do so. Dolores says:

> My first attempts to find care were kind of hit or miss, because my parents were not behind me getting involved in therapy. They're from a different generation altogether and they didn't want people knowing that I was going to be in care.
<table>
<thead>
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<th>Common Theme</th>
<th>Thomas</th>
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<th>Dinah</th>
<th>Dolores</th>
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<td>N/A</td>
<td>Speaking Up for Needs and Making Decisions about Care, Speaking Out</td>
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<td>Having Responsibility and Doing Good Work</td>
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<td>Pursuing a Career Being Supported in Professional Goals</td>
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<td>Trauma and Stress in My Life</td>
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<td>Trauma Affecting Functioning</td>
<td>N/A</td>
<td>I Just Couldn’t Function</td>
<td>N/A</td>
<td>Trauma and Cutting</td>
</tr>
</tbody>
</table>
As a result of this lack of support from her family, Dolores had to pursue treatment without the input or encouragement of those closest to her. Although Dolores doesn’t talk about how her parents’ perception of mental healthcare affected her own feelings about seeking it out, one can imagine that an individual in this situation might feel that it was shameful or that it was a socially unspeakable choice. In a different sense, Dinah’s family also impacted the choices she made for her own care, though her experience was in some ways the reverse of the one that Dolores faced.
While Dinah feels ambivalent at best about taking psychiatric medication, her family feels strongly that she should do so and Dinah resents their involvement in this aspect of her decision making about care. She explains:

I had people who would just say, “Take your medicine, take your medicine, take your medicine” in my family, so my boundaries with them and healing those relationships is taking some time because I still never forget, although I forgave them for their role, because they had a lack of information.

Here, Dinah speaks to an aspect of the complex experience of mental health consumers and their families trying to navigate and negotiate what level of involvement family members should have in planning and decision making around issues of mental healthcare. Dinah’s particular experience is that her family does not respect her desires and independence. Dinah attributes this, in part, to her family’s lack of information about how they might handle the situation differently and what the options were for Dinah outside of medication. Dinah places the blame for this on the mental health care providers for failing to orient her family in this regard.

While Dinah understands her family’s actions and their impact on her as being the result of a lack of information and orientation provided to her family, Dolores’ narrative touches on an experience of family as antagonistic to her mental health and well-being. In the theme, How Family Impacts Coping, Dolores says:

One of the first psychiatrists that I was with for about ten years, at one point he said to me and he said it to my parents too, he said, “I get her feeling better about herself and then she comes home to the family life and she's down again and being taken down,” and he said, “that's not working to help her.”

Dolores’ experience illustrates the profound impact that family can have on an individual’s
mental health beyond influencing their involvement in care. While Dolores was actively pursuing care, the negative impact of her family interactions undid some degree of the positive impact of the care she was receiving. These themes are summarized in Table 7.

**Abuses of power.** While all of the participants’ narratives touch on issues of power dynamics and the vulnerability inherent in being a mental health consumer, Dinah and Dolores speak more directly to fears about or experiences of abuses of power that they are susceptible to specifically because of their mental illness. In the theme *Fearing Their Power and Not Trusting that I’ll be Treated Well*, Dolores talks about sometimes holding back out of fear of that vulnerable position. She says:

> I didn't say too much because you feel like they're in the power and they can do what they want if they so desire. I feel like, well I don't want to end up in the hospital, so I better not say anything about this or that.

Dolores’ description of policing her behavior so as to avoid negative outcomes that she might be at risk of as a mental health consumer is similar to Dinah’s account of an experience at the Department of Motor Vehicles where she purposefully minimized her response to mistreatment by a Department of Motor Vehicles employee knowing that she was vulnerable to disproportionately negative outcomes if others perceived her as being emotionally elevated.

Anxiety about abuses of power is present in Dinah’s narrative in the themes *Rights Not Being Communicated* and *My Rights Were Obliterated*, where she outlines the differential she experienced as a mental health consumer during hospitalization and what she later learned as a professional. Dinah says of her hospitalization:

> It wasn't like the stuff I learned later about patients' rights being posted and having to know that you have the right to refuse. I thought I had been committed to this hospital
and later realized that I had signed paperwork so it was voluntary the whole time.

At the time of her hospitalization, prior to her education as a clinical social worker and her work as a mental health advocate, Dinah was not provided with the information she felt she needed in order to make the decisions about her care. Dinah says, “My rights were obliterated. No one told me, I didn't know. I really was shocked that I was even admitted to the hospital in the first place.” The sense of powerlessness that she experienced at the time of hospitalization and the retrospective realization of what had not been communicated to her at the time, was deeply painful and infuriating for Dinah. She feels that the treatment she received, not knowing there were alternatives, was inappropriate to her situation. These themes are summarized in Table 7.

**Speaking up, speaking out, and acting up.** As mentioned previously, both Leah and Dolores’ narratives contain significant examples of having taken a stand and voicing their opposition at moments when they were being treated in a way that they felt was unethical or unfair. Dolores, despite often feeling at the mercy of her care providers, has also shown significant ability to create change when her needs aren’t being met or when she feels that a boundary has been overstepped. A prime example of this, within the theme *Speaking Up for Needs and Making Decisions about Care*, was Dolores’ handling of the vocational support staff member who she felt was trying to sabotage her progress. Dolores explains:

> After having humiliating experiences with her, I finally did switch with the help of an advocate who came in and we talked with her boss and I just switched to somebody else.

Dolores, despite the differential power dynamic, was able to take the steps to address the problematic working relationship she found herself in by successfully reaching out to the other existing supports she had and clearly communicating her needs. While on some level this seems like an unremarkable step for her to have taken, when considering the power dynamics of the
relationship with the support staff member and the often-disempowered position of consumers of mental health, the fact that Dolores took action becomes deeply important.

Another major example of speaking out and taking action is shown in Leah’s narrative. In the theme *I Take Great Pride*, Leah outlines her decision to report the sexual abuse being perpetrated on her by her psychiatrist. She describes her initial reporting of what had happened:

I happened to be in a DBT program at the hospital the psychiatrist worked at . . . When I went in for the intake, I said, “Somebody on staff is abusing me. And he's diverting meds.” I thought they were just going to gloss over it. The next time I came in, a bigwig, the Director of Medicine or something, was there. He said, “Tell me. Right now. Tell me what is going on.” I told him.

While Leah wasn’t confident that her report would be acted on, she nonetheless took the extraordinary step of speaking out. Like Dolores, there were aspects of Leah’s experience that went beyond purely the power dynamics of a mental health care provider and consumer. Leah’s choice to take action also had to work against her history of trauma and her many prior experiences of not receiving the support and protection that she needed and deserved. These themes are summarized in Table 7.

*Treatment that feels effective and supportive.* Dinah and Thomas lay out some of the changes they’ve seen in how mental health providers interact and work with mental health consumers over the years. Dinah describes the shift she’s experienced in working with her psychiatrist over the past 10 or 11 years. She says:

I feel like my psychiatrist, at least, is getting it and he understands. He's not certain what the outcome will be with me, but at least he's willing to work with me . . . I've seen this psychiatrist since 2006, maybe 2005 or something, he's been my psychiatrist for all this
time. And so he's seen my growth and development as a human being and as a professional and I think that has probably made a difference for him. You can't be in behavioral health in this state without knowing that recovery is possible, I don't think . . . It's real for people.

In the theme *Treatment that Feels Humane*, Dinah attributes this shift to her psychiatrist being able to see her growth and development over time. Dinah talks about him seeing that “recovery is possible,” but beyond that one can imagine that Dinah has also shown him what recovery means. Dinah’s trajectory, and that of the other participants over the past 15 years, is recovery made real, proof that how someone with a mental illness can live their life to its fullest potential.

Building on Dinah’s observations, Thomas describes some specific changes that are taking place within the Clubhouse that reflect this shift. Thomas explains that in the past, there had been a system of rules that resulted in gradually increasing “consequences” for Clubhouse members who broke these rules. However, in the theme *Being Advised Instead of Punished*, Thomas speaks about the modifications to this system that are underway:

A recent development is a new system where the person would have somebody counsel them about the problem and they're shown ways that they could do things differently so that they wouldn't cause problems. I don't know how it will work yet, because they just changed over to the new system . . . I have a feeling, just a hunch, that the fact that there isn't a punishment for their behavior, will make some people more comfortable. Instead of a punishment, they are actually advised as to what to do.

These alterations represent a movement away from behavioral limits and negative reinforcement to a model that, at least in theory, encourages and supports positive change within the individual. Thomas is hesitant in his promotion of the new system, suggesting that it may work better for
some Clubhouse members than others but the language he uses here is telling. The move away from “punishment” and towards “advising” the Clubhouse members seems like a relevant indicator of how approaches to treatment are being rethought and experienced by those receiving the treatment. These themes are summarized in Table 7.

*How mental health care has shifted or changed.* In their narratives, Leah and Dinah speak to these same changes in mental healthcare on a much broader scale. Looking back over her experiences of treatment, care, and hospitalization, Leah reflects, “Treatment varied, it varied, but the system was starting to improve.” Rather than finding a continuous forward motion towards improvement, Leah describes a transformation that has happened in fits and starts, improving overall but not seamlessly and not across the board. Dinah explores this further in her narrative in the theme *Mental Health Care has Changed, but the Status Quo is Hard to Change.* She says:

> We have a voice and I have a voice today that I didn't feel was being heard by service providers before. I still think there's some service providers who don't hear me when I speak, who don't recognize that we do have choices. As people with a mental health condition we have a choice. Ultimately the choice should lie within us.

Dinah touches on the theme discussed earlier as a point of convergence across the narratives, *Being Respected, Listened to, and Involved.* There is a general movement towards acknowledging the agency of mental health consumers and valuing their input and desires. However, as Dinah points out, this change hasn’t happened across the board and there are still providers who engage with consumers in old, familiar ways. It is perhaps Dinah’s own certainty about the fact that care choices lie within consumers rather than with their care providers that signifies one of the more important shifts in the field.
However, Dinah also offers us a cautionary tale. In her most recent therapy, Dinah describes working in ways that, while they seem to adhere to the goals of the recovery model on the surface, did not do so in practice.

I think we have a long way to go . . . Even with the third therapist I had, an old treatment plan was still being used, just to get you to sign it so that they could get funding. Probably it was partly due to my lack of insistence that I be a part of the treatment planning. I think that still is an area that needs to be addressed . . . Even me, knowing and teaching it, I still go to a facility and on the most recent treatment plan I signed, I really just signed it. We didn't have a conversation first about what my goals are, although she knew that I want to get a job as a social worker, that's not in there.

Dinah’s experience is a reminder of how easy it is for us, even Dinah with her extensive advocacy training, to continue the status quo. Integrating these changes fully would mean stepping outside of what feels comfortable and familiar to us and takes an effort of will that can be hard to muster, even knowing that it is needed. Dinah voluntarily shoulders some of the blame here, pointing out that she did not question the use of a treatment plan that she knew to be out of date and did not insist on it changing to reflect the changes in her. This is a deeply relevant reminder that integrating recovery oriented practices in mental health care goes beyond an alteration in programmatic language and policy. Much of the work must take place in individual interactions between care providers and their clients and this is an area in which the transformation may be at risk of petering out. These themes are summarized in Table 7.

**Notable differences or themes specific to individual participants.** Three of the four participants’ narratives contain themes that are unique to their narratives and not shared across
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<td>Getting Involved with Cooking</td>
<td>What Propels Me Forward</td>
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<td>Wanting to Provide Better Food</td>
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<td>Staff are Dictatorial Across Settings</td>
<td>The Impact of Hearing Voices</td>
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<td>Staff Need to Provide Support and be Patient</td>
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<td>Wide Range of Recovery</td>
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<td>Clients Being Disciplined</td>
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<td>Limited by My Disability</td>
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other narratives. With regard to the one participant, Leah, whose narrative does not contain unique themes, I think this difference can be understood as in part a result of much of Leah’s narrative dealing with her experiences of trauma. While no other participant speaks about their trauma in that detail or length, Dolores’ narratives also contain themes regarding trauma. The narratives of other participants are more varied and therefore contain themes that do not overlap with one another. Although all of these themes are important in different ways to the individual narratives, a number of them touch on areas of the individual’s experience that are less related to their experiences of care, so I will only explore those that stand out as important in relation to that question. For this reason, I will not be exploring the themes unique to Dolores’ narrative as none of them directly pertain to the question of her experience of care. These themes are summarized in Table 8.

**Thomas.** Thomas’ narrative contains unique themes that broadly break down into two categories: those related to his professional experiences at the Clubhouse and the safety and comfort of the Clubhouse community and those related to his experiences of mental health providers across settings. Under the theme *Having a Sense of Stability and Security*, Thomas talks about what he has gained from his professional development. He says:

> I feel like I have a marketable skill as a chef. So, I feel like if something happened or for some reason the program closed or if I was laid off, that I could get work as a cook. So there's a sense of stability and security.

Thomas repeatedly touches on his uncertainty and anxiety about the future, particularly in terms of navigating the eventual passing of his parents and finding appropriate services and supports without the help of a case manager or therapist, but the one area in which he does not express uncertainty for the future is professional. While there are some aspects of his work at the
Clubhouse that are distressing for Thomas, as will be explored below, his position there has
given him certainty that, whatever happens, he will be able to land on his feet. The training and
experience he has gained in this position give him a sense that he is employable and capable of
meeting the requirements of a challenging position.

Despite feeling well prepared for employment outside of the Clubhouse, Thomas speaks
about what a unique and safe place the Clubhouse has been for him. In the theme The
Importance of a Safe Place, Thomas compares the safety of the Clubhouse with professional
experiences that he had outside of it.

I feel like I'm in a safe place where I am. I feel more secure at the Clubhouse. I think that
if I were to leave that environment and go out into the community, I might be treated in
the same where I was before, where I was put down. Or maybe, if I was in a situation
where I was having some kind of psychotic symptom, people might not understand
what's going on and there might be some kind of serious consequence to that . . . I did
have some trouble when I was working outside of the Clubhouse. Some people, when I
disclosed my illness to them, abused me. People, for some reason, put me down, because
I had a disability. The Clubhouse is a very safe place. For the most part, people
understand where you're coming from.

Thomas recognizes that, unfortunately, the safety and acceptance that he’s experienced at the
Clubhouse is not guaranteed outside of it. While he does not always receive encouragement or
pure support from his supervisors at the Clubhouse, Thomas can depend upon their acceptance of
his mental illness and their understanding should he experience symptoms or decompensate. To
be an employee with a disability in a typical work environment comes with serious risks.

Even at the Clubhouse, there are times that Thomas feels criticized for his limitations and
he explores this feeling in the theme *Limited by My Disability*:

I do get a sense from the staff at the Clubhouse that my disability does limit my work ability somewhat. I feel like I'm running up against limitations . . . I have to try to write everything down because when they give me a lot of information, sometimes I can't remember it all and then sometimes I will forget that I had to do certain things. So, when that happens, sometimes I get criticized.

Thomas understands this as being in part due to the staff trying to create the same expectations that Thomas might face in a typical professional setting. But there are ways in which this experience mirrors what Thomas imagines might happen in a job in the community if his mental illness were disclosed that go beyond the establishment of professional standards. Although Thomas isn’t being explicitly put down for his “disability,” he is made to feel the connection between his mental illness and the staff’s occasional criticism of his job performance.

Thomas also speaks more generally about his experiences of mental health providers across various settings in the theme *Staff are Dictatorial Across Settings*. He describes some broad differences between how providers in hospital settings and those in the Clubhouse engage with mental health consumers, while also pointing out the similarities between the two.

Some of [the staff at the partial hospital] were not well suited for working in mental health treatment. They weren't sensitive to the clients. At the Clubhouse, they're more sensitive to our needs and so forth. Although, in both places there is kind of a dictatorial side to it.

Thomas identifies a greater level of sensitivity in the mental health providers working in the Clubhouse setting, implying that this is a necessary character trait for those working in mental health, while also pointing out that there is a unifying experience of mental health providers in
both settings being “dictatorial.” He says, "The staff at the partial hospital program and at the Clubhouse are very similar in the way that they approach things.” The approach that Thomas is speaking about seems to relate to providers engaging with consumers in a way that highlights the provider’s authority. In comparing the two directors that he has worked with at the Clubhouse, Thomas says, "The current director is . . . a ‘manager-type.’ They were both ‘manager-types.’ The current director definitely wants to keep things running smoothly and she wants to be authoritative." Thomas seems to equate, or to say that these directors equated, being authoritative with things running smoothly at the Clubhouse. Elsewhere, Thomas talks about the necessity of providing “discipline” for some of the clients at the Clubhouse who would otherwise disregard the requirements and rules of the Clubhouse.

However, Thomas’ explanation of the recent change in how clients at the Clubhouse will be dealt with when they “break the rules” suggests that he is also attuned to the emotional impact of engaging with staff who are “dictatorial” rather than those that encourage different behavior. In the theme Staff Need to Provide Support and be Patient, Thomas speaks about the delicate balance that he believes is required of mental health providers.

[Staff at the Clubhouse] have to be able to direct [clients] and help them, show them what to do. And they also have to have a patient side; when they're trying to teach something to a client, they have to be very patient with them and work with them, supervise them and show them what to do.

While Thomas does say that he believes staff need to be able to “direct clients,” he describes this as staff showing clients how to do things differently, working with them to create change. Notably, Thomas’ description of the recent alterations to the rules at the Clubhouse seems to reflect exactly this balance of working with clients to shift behavior in ways that aren’t punitive
or directive.

**Dinah.** There are two themes in Dinah’s narrative that are particularly unique to her and speak directly to her experience of care. The first of these, as mentioned previously, is the theme *Treatment is Based on Appearance.* Dinah repeatedly touches on this in her narrative, underlining the greater risks she faces as a woman of color and the ways that one’s physical characteristics affect one’s treatment. In describing one of the instances in which she was physically restrained while hospitalized, Dinah explores how her features and presentation shaped the actions of the hospital staff. She says:

> At the time I was restrained, my hair was in locks, you know, I might have looked bigger, I weighed more, I'm not saying there's a difference, but I'm saying there's a difference in how you're treated. And I would say I was restrained by at least seven or eight people, most of them were men.

It is hard to miss Dinah’s point here. If, as she states, Dinah was not physically aggressive in any of the instances in which she was restrained, the idea that seven or eight men would be needed to restrain her does suggest that it is Dinah’s physical characteristics that the staff read as so “dangerous” as to require an extreme level of restraint.

Beyond the experience of restraint, Dinah speaks to the kind of navigation that all mental health consumers face in attempting to present in ways that will avoid negative outcomes. There is a level of calculation that she suggests is required in engaging with mental health providers in the system.

> I learned that there's a certain way a patient has to talk in order to be heard and in order to have what we desire to have. And so what I did was agree to take the medicine so that they would let me out of that facility at some point . . . And then I went and I saw a
doctor and learned quickly that when you go through the many mental status exams that there are certain ways you have to answer those questions and there's certain ways you have to look in order to for the providers to view you a certain way.

Dinah’s description implies that at times interactions with mental health providers are more about a client consciously replicating the behavior they know the provider is seeking rather than accurately representing their experience. Though Dinah does not specify what it is that providers are looking for or wanting in those interactions, in reflecting on her assertion that no medication she has ever taken has removed her auditory hallucinations, one can imagine that a consumer might make the choice not to share such information with a provider, knowing that the presence of auditory hallucinations might be seen as unacceptable.

Returning to Dinah’s experience in restraint, one of the unique aspects of her narrative is her description, in the theme *Dealing with Traumatic Experiences in Mental Health Care*, of the experience of being in restraint and how she coped with it. Dinah says:

Thank god, I had practice in my undergraduate life with transcendental meditation and yoga, because the only way to deal with four-point or two-point restraint is to go inward, to try to calm yourself. Because what happened is . . . my blood pressure went through the roof and I'm in these restraints and you can't move and you can't scratch or whatever, you can't do anything. You can only free yourself within and so that's what I did in order to get through the experience until they removed the restraints.

Dinah’s account of being physically restrained is a vivid illustration of animal fear and the feeling of being trapped. Dinah describes using meditation to cope with this fear, but one can imagine that another mechanism that might come into play would be a dissociation of self. Dinah hints at this possibility, if not for herself than for other individuals, in her statement that the
experience of restraint evoked the sexual violations she had experienced in her childhood. This underlines Dinah’s assertion that restraint cannot be considered therapeutic in any sense, but is clearly punitive. One is reminded here of Thomas’ description of the difference between punishment and adjustment. If restraint is punishment, than what is it that is being punished?

**Reflexive Analysis**

**Summary of the researcher’s a priori interests, expectations, and assumptions.** As described previously, I entered into this project with certain assumptions about the typical experience of care for mental health consumers, based on my work in the mental health field before beginning graduate school and my observations in various training settings during my time in graduate school. My professional experiences prior to beginning graduate school showed me that organizations that subscribed to a recovery-oriented model of care did not always succeed in upholding the tenets of the model in the actual care and support that was provided to their clients. In fact, in many ways, despite a change in model, clients in these programs still seemed very much at the mercy of the stigma, abuses of power, and disengagement of the providers who worked with them. This raised some important questions for me in considering both the potential impact of recovery-oriented care and the barriers to its successful implementation. Given what I had seen of programs that attempted to work within the framework of the recovery model, I wondered how those on the receiving end experienced recovery-oriented care and whether there were any identifiable differences to consumers who had previously been in other systems of care.

In beginning to explore this question, I was surprised to find, as described previously, that no research had yet looked at the qualitative experience of the consumers of recovery-oriented care. This seemed an important omission given the recovery model’s aim of
empowering mental health consumers to more actively participate in their own care. In proposing this study, I sought to create a platform for and to amplify (even on a modest level) the perspectives and experiences of mental health consumers, as those most intimately affected by the care. My hope was that, if there were crucial ways in which recovery-oriented care was failing to meet its goal of changing the experience and impact of mental health care, this research might begin a dialogue about why that was the case. I also hoped to contribute to a shift towards inclusion of the voices of mental health consumers in research aimed at assessing the impact of systems of care.

In terms of my expectations and assumptions about the results of the research, I anticipated there might be a certain disconnect between an organization’s espoused position and the actual experience of the mental health consumers who received care within the organization. What I felt unable to predict was how this might play out in a state such as Connecticut, in which the recovery-oriented model of care was the state-sponsored rule rather than the exception. On a certain level, I expected that, as I imagined being true elsewhere, there would be variation in how well or how completely organizations had fully implemented the recovery model.

Perhaps less reflected in the outcomes of the research were my expectations about the mental health consumers that I might come across in the study. Despite my own knowledge of the diversity of situations and circumstances among mental health consumers, I had in mind a particular image of a mental health consumer clearly based on biases that did not reflect the facts of this study’s participants. I envisioned a mental health consumer whose involvement in mental health services had been continuous, and for whom the services had stayed mostly static, since they began receiving care. Additionally, I imagined mental health consumers of a far different level of functioning than the participants I interviewed. To some degree, it’s possible
that my assumptions might have played out if I had succeeded in recruiting participants from the community mental health center that I initially partnered with, but they certainly did not prove accurate for those I did succeed in recruiting through the Regional Mental Health Board. These assumptions on my part are important to note, because they reflect the deeply entrenched nature of the stigma and biases described in the literature review (Cosgrove, 2005; Deegan, 1993; Flanagan & Davidson, 2009; Lester & Tritter, 2005; Roe & Davidson, 2005; Stier & Hinshaw, 2007; Yennari, 2011). Even as someone with an extensive understanding of the baselessness of these well-worn narratives of uniform and persistent deficit, consistent decline, and negative trajectory, who positions myself as an advocate for mental health consumers, these stereotypes are tenacious and pernicious.

The experience of interpretation and analysis. In many ways, I found the experience of interpretation and analysis quite difficult. As described in the Exploration of the Interview and Analysis Process and Key Themes in Each Narrative, the process of analysis sometimes appeared forced or arbitrary. I often felt as though different meaning units lacked clear outlines and were utterly random. This perception does of course hold some truth, but is not wholly accurate. There is fluidity to the designation of a meaning unit that is a necessary aspect of the subjective gaze of a researcher, and yet the unit of meaning as it is delineated does represent the existence of certain themes. Another aspect of the work of analysis that I found difficult was making sense of the sections of the narrative that seemed to hold little meaning but instead were factual responses to my questions in the interview. In the analysis, I felt frustration as well as the sense that these were the products of my failure to structure and guide the interview in more fertile or productive directions in those moments.

A particularly difficult aspect of the interpretation and analysis came up for me in
working on Thomas’ narrative. I felt that there were ways in which portions of the narrative seemed to denigrate certain individuals with mental illness or individuals with mental illness in general. I wondered whether this was something I was projecting onto Thomas’ narrative or whether it was in fact present within the narrative. I wondered whether, if this were in fact part of Thomas’ narrative and not just my projection, this was a learned perception or judgment that he had absorbed from society at large or whether it was a deeply held belief and observation of the behavior of other mental health consumers. A question that was quite difficult for me to answer was what my own responsibilities were in including and handling that aspect of Thomas’ narrative.

As mentioned previously, I found the process of interpretation and transformation challenging. Although transformation is of course part of the interpretive process, I found it difficult to tread the middle ground between clarification, translation, and reinterpretation. I had the sense that there was a necessary kind of violence to the process of interpretation and transformation in which I was attempting to bend another’s meaning and subjective experience to fit a narrative that was accessible to me. Though of course my intention was to accurately reflect the participant’s experience in their narrative, the clarifying and reordering of their words necessarily removes the narrative from being purely in the realm of their experience and positions it outside of them. These narratives feel, in many ways, as though they are only a reflection of the participants’ experiences.

**Explication of the results in the light of the researcher’s implicit assumptions.** In considering the results of the qualitative analysis in light of my interests, expectations, and assumptions, I will attend to how these may have impacted or come into play with the themes that I identified in the narratives. For the most part, the four themes that were common to all of
the narratives aligned with my expectations. Based on what I have witnessed or learned of mental health consumers’ experiences of care, I assumed that all participants would have had negative experiences at some point in their involvement with mental health care. While it is certainly possible that my expectation influenced the existence of the theme *Treatment that was Unsupportive, Unwarranted, Dehumanizing, or Traumatic*, I do not believe this was the case given the presence of the theme in the interviews with all four participants. Similarly, the shared theme of *The Impact and Effects of Choosing to Take Medication* aligned, for the most part, with my expectation that medication would be an aspect of treatment that participants engaged with ambivalently. As with the previous theme, the presence of comments regarding the impact of medication across all four narratives suggests a more consistent finding than might be entirely accounted for by my expectation that this theme would be present.

The common theme of *Being Respected, Listened to, and Involved* was certainly a hoped for result, but not one that I necessarily expected to see. As described previously, I was uncertain if there would be any felt changes in how providers engaged with clients. It is possible that participants presented this theme in their narratives because they assumed it would be a desired result, but I do not believe this to be the case. Elsewhere the participants appeared willing to identify aspects of their care that continued to be unsatisfactory, which leads me to believe that they felt able to express this feeling in the context of the interview. The one common theme that was unexpected was that of *Support in Many Forms*. While there were aspects of it that I had anticipated, such as the loss of support over time, I was surprised that only two of the participants, Thomas and Dolores, seemed to feel the loss as such. As I will explore more fully, my expectation that the loss of support would be have been detrimental to the participants’ well being may reflect my image of the participants as rooted in a position of deficit and need. It is
also certainly possible that the difference between the four participants in this common theme reflects the differences in my experience of the participants. Leah and Dinah both presented as highly capable and articulate individuals who engaged readily and easily with the questions I asked in the interview. Thomas and Dolores, as described previously, struggled somewhat more in responding. This may have impacted my perception of their abilities and thus affected the way in which I asked questions about how they felt regarding the loss of support.

The majority of themes common across three narratives also aligned with my expectations. Not Being Respected, Listened To, and Feeling Powerless represents many of the same previously mentioned widespread cultural narratives of mental health consumers and mental health care and also confirmed instances I had witnessed in which mental health consumers and been treated or engaged with in ways that were similar to what the participants described. The same was true for The Process of Recovery and Lack of Support or Lack of Therapeutic Connection. An unexpected theme in this section was that of Making Choices About Care, in which Leah, Dinah, and Dolores described their active attempts to access care, how and when they wanted or needed to. While this theme wasn’t actually contrary to my expectation, it proposed a level of existing engagement and agency around pursuing care that I had not anticipated.

One of the themes present in Leah and Dolores’ narratives, Speaking Up, Speaking Out, and Acting Up, was similarly unexpected. It is perhaps a reflection of the embeddedness of the narrative of consumer deficit that I had not anticipated any of the participants taking such active steps to advocate for themselves in situations in which they were very much at the mercy of care providers or staff. I was particularly struck by Leah’s description of the steps she had taken to get herself out of psychiatric hospitalization while young and pregnant. There was a sense of
purpose and a certainty of direction that I found both remarkable and heartening in Leah and Dolores’ narratives as they related to this theme. Similarly, in one of the themes unique to Thomas’ narrative, *My Confidence Comes from Myself*, Thomas speaks to a sense of pride in his skills and his abilities, which he experiences as coming from within rather than being the result of external support. Like Leah and Dolores’ self-advocacy, this should not be a remarkable thing. And yet, I believe that because of the paucity of narratives readily available that speak to the strengths of individuals with mental illness, these themes within their narratives are, in fact, deeply important. It seems possible that the absence of these narratives, both in society at large and in the mental health field specifically, hints at the pervasive language and image of disability and loss of strength, skill, or ability that Deegan (1993), Lester and Tritter (2005), and Stier and Hinshaw (2007) describe.

As with the way in which these themes of strength, self-confidence, engagement, and agentic action were unexpected and unanticipated, the significant degree to which the particular participants who took part in this study diverged from my expectations is deeply relevant to understanding the impact of the pervasive cultural stigmatization of mental illness. Rather than participants who had been involved continuously in a homogenous treatment, the individuals that I interviewed reflected the broad scope of experiences among mental health consumers. The ways in which the participants and narratives differed from my expectations points to my failure to account for the diversity in experiences of severe mental illness and the unique treatment and recovery trajectories of individuals. This is notable because it suggests that despite the progress that has been made in the mental health field, historically held beliefs about mental health consumers persist in shaping our unconscious assumptions in the present. These persistent stereotypes and stigma presumably continue to shape our engagement with mental health
consumers as well as the development and implementation of care. The existence of these assumptions in my own formulation of the research underlines for me the continued importance of interrogating the root of beliefs that we, as mental health providers, might not otherwise challenge.
Chapter Four

Discussion

Reflection on the Purpose of the Study

As laid out in the introduction, there has been a shift over the past few decades towards a recovery-oriented approach to care for individuals with serious mental illnesses such as schizophrenia (Davidson, 2003; Davidson & Roe, 2007). The recovery model has gained widespread acceptance to the point that it is now the sanctioned approach to care for many institutions, states, and countries (Anthony, 2000, p. 160; Davidson, O’Connell, Tondora, Styron, & Kangas, 2006, p. 640; Davidson & Roe, 2007, p. 460; Marshall, Oades, & Crowe, 2009, p. 654; Piat & Lal, 2012, p. 289). Despite this, it has proven difficult to implement a recovery model of care in a comprehensive and consistent way. Research suggests that, for mental health providers, there is a disconnect between the acceptance of the theoretical underpinnings of recovery oriented care and an actual application of the model (Bedregal, O’Connell, & Davidson, 2006; Piat & Lal, 2012). The research that has sought to understand the mental health consumer’s perceptions or experience of recovery oriented care has typically relied on surveys or other assessment tools to measure the consumers’ experiences (Barrett et al, 2010; Marshall, Oades, & Crowe, 2009; O’Connell et al, 2005). This research was, of course, vitally important in beginning to understand the landscape of the consumer’s perspectives on and experience of recovery-oriented care, but a gap remained in our understanding of the consumer’s lived experience of the recovery model.

My hope for this study was to begin a dialogue, on the smallest scale, that more fully incorporated the experience of consumers into the mental health field’s understanding of the benefits and pitfalls of recovery-oriented care. I believe that in taking these experiences into
consideration and using them to help shape our implementation, we might better succeed at
upholding the theoretical stance of the recovery model.

Contributions of the Present Study

As described in the Results section, there were four themes that were common across all
four participant narratives. For the most part, these common themes affirmed already generally
accepted aspects of discourses around mental health care and mental health consumers. The
broad theme of *The Impact and Effects of Choosing to Take Medication* is a prime example of
this. While the participants’ experiences of taking psychiatric medication are of course important
aspects of their narratives, the complicated, often ambivalent relationship that mental health
consumers have with psychiatric medication is widely recognized and has been explored
elsewhere².

The shared theme of *Treatment that was Unsupportive, Unwarranted, Dehumanizing, or
Traumatic* is a vivid illustration of the ways that mental health care has often been, and
sometimes still is, experienced as inhumane, punitive, or ineffective. Dinah’s narrative in relation
to this theme is of particular note because of the unique perspective it offers on the experiences
of people of color. Dinah was the only participant who spoke about being restrained during
hospitalizations and, while it is certainly possible that the other participants had also been
restrained at some point during their hospitalizations, this may be indicative of her experiences
differing from that of other participants. Dinah speaks about these restraints as occurring as the
result of behavior that did not endanger anyone else and was, at most, merely disruptive. Despite
this, Dinah says that she was restrained by eight people, double what might be considered

² For an excellent exploration of the topic, see Roe, Goldblatt, Baloush-Klienman, Swarbrick,
and Davidson (2009).
typical, and then strapped to a gurney for several hours. This lends weight to the assertions of Fernando (2010) and Whitaker (2010), who suggest that African-Americans are more likely receive extreme interventions than other mental health consumers. It also indicates continued instances in which disruption or inconvenience for the provider is given more consideration than the well-being or desires of the client (Gray, 2009).

The shared theme *Being Respected, Listened to, and Involved* suggests that one of the aspects of a recovery-oriented approach to care that has been successfully implemented is the increased inclusion of the client in making decisions about care. As Dinah’s narrative shows, this does not necessarily mean that mental health consumers are supported in pursuing alternative treatments, but clients do have a greater degree of input in decisions and independence in choosing when to pursue one treatment over another. Leah, Dinah, and Dolores all talk about feeling empowered to evaluate and choose care and to engage with new or different supports when their needs change (*Making Choices About Care*). Dinah and Thomas describe the shifts in mental healthcare that have made room for and encouraged the active decision-making of consumers (*Treatment that Feels Effective and Supportive*), speaking about an increasing openness and trust on the part of mental health providers who work with consumers. Thomas talks about modifications to the “enforcement” of the system of rules that exist at the Clubhouse and the staff’s new approach to addressing transgressions, which involves working with consumers to create positive behavioral changes.

In addition, the participant narratives point to other supports that have buoyed recovery. Thomas, Leah, and Dinah describe the importance of cultivating professional and personal development (*The Process of Recovery*). Thomas highlights the importance of creating areas of stability (professional or personal) in the individual’s life, to sustain them through times of
uncertainty (*Having a Sense of Stability and Security*). For Thomas professional training and experience provide this security, Leah finds stability in her professional and romantic relationships, and Dinah suggests that her social relationships and advocacy work provide her with a similar foundation.

Despite these positive shifts in mental health care, Thomas, Dinah, and Dolores identify areas in which there is still significant work to be done (*Not Being Respected, Listened To, and Feeling Powerless* and *Lack of Support or Lack of Therapeutic Connection*). The participants speak about interactions with providers that make them feel disregarded, belittled, or disrespected. Thomas describes being made to feel disadvantaged by his mental illness by staff and providers who point out his occasional failure to live up to their expectations (*Limited by My Disability*). Themes in Dolores and Thomas’ narratives echo Lester and Tritter (2005) and Stier and Henshaw’s (2007) findings that individuals with mental illness often experience stigma in the form of a perceived diminishment of their value and abilities.

Experiences of oppression associated with a diagnostic label were also present in the narratives of all four participants, although they were located in very different themes. While he is speaking about an experience that occurred outside of the mental healthcare he receives, Thomas touches on the vulnerability of being an individual with mental illness in settings where this is neither understood nor handled respectfully (*The Importance of a Safe Place*). But participants experience oppression in mental healthcare as well. Dinah talks about her retrospective awareness that during her hospitalizations, there was an insufficient communication of client’s rights, both to her and to her family (*Abuses of Power*). Like Gray (2009), Dolores speaks about a sense that she must police her behavior and comply with the desires of staff and providers to avoid disproportionately negative outcomes (*Abuses of Power*). Dinah shares this
feeling and she talks about the calculation that consumers often have to engage in in order to navigate interactions with individuals who have the ability to penalize behaviors that are seen as objectionable or “out of line” (Treatment is Based on Appearance). Thomas’ narrative suggests that the uncomfortable power dynamics present in relationships between mental health consumers and providers can be seen across settings (Staff are Dictatorial Across Settings).

However, Thomas, Leah, and Dinah speak to gradual improvements that they have seen in their interactions with providers and the mental healthcare system. This progress has happened slowly and has not happened across the board, but has nonetheless been felt in interactions with providers and in the care that they have received (How Mental Health Care Has Shifted or Changed and Staff Need to Provide Support and be Patient). Despite these positive changes, Dinah points out that even clients and providers who are aware of the conversations they are expected to have and work they are meant to do in incorporating the recovery model, sometimes let these conversations and tasks fall to the wayside. As expected, even with the best of intentions, it is at the level of direct interactions that recovery-oriented care sometimes falters. Dolores and Leah’s narratives offer us hope though, showing that even in moments of extreme vulnerability, individuals with mental illness are capable of remarkable acts of self-care, bravery, and resilience (Speaking Up, Speaking Out, and Acting Up). While the burden remains on the mental healthcare system to making sure that recovery-oriented care is implemented, it is a useful reminder that mental health consumers have a strong sense of what changes have not yet been made and the ways we could better meet their needs.

Limitations of the Study

There were several limitations to the present study, some of which were anticipated and some of which arose over the course of the study. The initial proposal for the study laid out my
intention to recruit potential participants from sites or programs that provided mental health care. Recruiting participants from such a setting might have ensured that potential participants were making use of a higher level of care than that of the participants I ended up interviewing and might have resulted in participants who were receiving a more uniform set of services and supports. The four participants I interviewed were, for the most part, currently receiving a lower level of care and a fewer services than I had anticipated in proposing the study. One could therefore argue that the study does not accurately reflect the general experience of recovery-oriented supports and services offered by sites and programs.

As described in Participant Recruitment, the potential participants who did express interest and met the requirements for the study were recruited through a Regional Mental Health Board. Their connection with the Regional Mental Health Board indicates that all four participants had pre-existing interest in issues of mental health advocacy. Additionally, this group of participants had all previously participated in research either as partners or participants. It could be argued that the location of recruitment and involvement of the participants with the Regional Mental Health Board suggests that the participants I interviewed were not a generalizable cohort. The fact that the participants dedicated their time and attention to the Regional Mental Health Board may indicate a greater level of awareness of instances of stigma and oppression and a certain level of functionality and the freedom and ability to pursue concerns around advocacy. However, even within the group of four participants, there were differences in levels of functioning and variation in their prior experiences of care.

Another limitation of the present study was the small number of participants who were interviewed. While the number of participants is within acceptable limits for qualitative research, I had initially hoped to recruit at least six participants, allowing for the practical use of pilot
interviews. This may also have resulted in greater diversity among participants and lent greater weight to the results. Of course, the difference between four and six participants would not have changed the nature of the study, which I have always understood to be a pilot study that might suggest ways to move forward with one of a larger scale.

**Suggestions for Future Research**

While the small sample size was appropriate for the project and time frame proposed here, a larger sample size would offer both a greater diversity of experiences and the potential for more commonality and overlap of participant narratives, strengthening the points of convergence. A larger sample size might also allow for recruitment of a more ethnically and culturally diverse group of participants. In addition, as I have explored elsewhere, I believe there might be significant benefit in again attempting to recruit within a specific site or program.

In the present study, the participant narratives all touch on the importance of supports outside of their mental health care. With this in mind, an exploration of the ways that mental health consumers make use of other supports in their life may provide us with a better understanding of how consumers access these supports and how these supports can be integrated in aiding in the client’s recovery.

Dinah’s narrative points to two avenues that might benefit from further research. In reflecting on her earlier experiences of hospitalization, Dinah talked about the difference between what she later learned about her rights as a client and what she felt she was told during those hospitalizations. This experience may bear further scrutiny, particularly if it is one shared by other mental health consumers and may have wider implications for how such information should be communicated to clients. The second avenue of potential research has to do with how Dinah’s status as a minority may have impacted her experience of treatment. Whether it reflects
an actual difference in experience or merely a difference in what was shared during the interviews, Dinah’s description of her hospitalizations diverged significantly from the other participants. Dinah was the only participant who explicitly stated the belief that she had been admitted to the hospital when she shouldn’t have been and who spoke about restraint that she believed was inappropriate. While research certainly supports the possibility that Dinah might have received interventions beyond those used for other participants, to my knowledge no qualitative research has yet explored the differences in the experience of Caucasian and minority mental health consumers in care.

Lastly, but perhaps most relevant to the current study, if indeed the direct contact level is where implementation of recovery-oriented care falters, than an important next step would be qualitative research that explored the provider end of the experience. Research targeted towards understanding the obstacles that providers experience in adhering to the recovery model in their work with individual clients may enable us to begin addressing those obstacles cooperatively with providers.

Conclusion

The history of our culture and mental healthcare system is fraught with, possibly well-meaning, but nonetheless stigmatizing and oppressive treatment of those with mental illness. Our efforts over the past several decades to improve the beneficial impact and quality of the care that is offered while also diminishing the stigma and oppression experienced by mental health consumers are laudatory but are in jeopardy of stalling or petering out (as other attempts have done before). If we truly hope to move towards a person-centered approach to care that supports an individual’s recovery from the negative impacts of mental illness (and all that entails), we cannot do so without incorporating the experience and feedback of those clients on the receiving
end of mental health care. Otherwise, we risk creating an echo chamber in which the only voices contributing to the discussion are those who propose and study the models of care in question, without being fully aware of the experiences such care produces for consumers.

The results of this study broadly support the idea that a number of important shifts have occurred in mental healthcare and that there have been significant improvements to the incorporation of the client’s desires and input in treatment planning. However, the results also suggest that as certain supports are rolled back for clients in the process of recovery, others are not introduced to meet their evolving needs. Additionally, there are some changes that remain incomplete, particular at the level of individual interactions between providers and consumers. Conducting these interviews also served as an important reminder of the variation within recovery. There is no single formula or trajectory appropriate for all consumers and a focus on measureable outcomes is perhaps less relevant than consumer feedback about whether they feel that their goals are honored and supported and their voices heard.
References


Appendices

Appendix A: Participant Recruitment Letter

Dear Sir or Madam,

My name is Sarah Hamilton. I am a doctoral student in the Clinical Psychology Program at Duquesne University. I am recruiting mental health care providers and consumers to take part in interviews. These interviews will be used for a study about experiences working in and receiving mental health care. This is an important topic that has not yet been fully explored. Mental health care is always changing and it is important to know what these changes are like for the people most affected by them.

I am looking for mental health providers who have worked in the field for at least fifteen years. I am also looking for mental health consumers diagnosed with schizophrenia, who have been receiving services for at least fifteen years.

Volunteers will be asked to take part in one interview. During the interview, volunteers will be asked to talk about their current and past experiences of mental health care. The interview will last about 1 hour and will happen somewhere other than the facility at which volunteers work or receive care. At a later time, volunteers will also be asked to read through an account of their experience of care in order to make sure that the account matches their experience. The Duquesne University Institutional Review Board has approved this project.

If you have any questions please contact me (phone: XXX-XXX-XXXX, email: hamilto4@duq.edu) or my advisor, Dr. Russell Walsh (phone: 412-396-5067, email: walshr@duq.edu).

Thank you for your time.

Sincerely,

Sarah Hamilton, MA
Duquesne University
Psychology Department
211 Rockwell Hall
Pittsburgh, PA 15282
Appendix B: Consent Form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: Clients’ and Providers’ Experiences of Recovery-Oriented Care for Schizophrenia: A Qualitative Research Study.

INVESTIGATOR: Sarah Hamilton, M.A.
Duquesne University
Psychology Department
211 Rockwell Hall
Pittsburgh, PA 15282
XXX-XXX-XXXX

ADVISOR: (if applicable) Russell Walsh, Ph.D., Associate Professor, Director of Clinical Training
McAnulty College and Graduate School of Liberal Arts, Psychology
412-396-5067

SOURCE OF SUPPORT: This study is being performed as partial fulfillment of the requirements for the doctoral degree in Clinical Psychology at Duquesne University.

PURPOSE: As a mental health care provider or mental health care consumer diagnosed with schizophrenia, you are being asked to take part in an interview about your experiences of mental health care. You will be asked to take part in one interview with the researcher. During the interview, you will be asked to talk about your current and past experiences of mental health care. The interview will be roughly 1 hour in length and will not take place in the building at which you work or receive care.

These interviews will be taped and transcribed for analysis.

At a later date, you will be asked to read through an account of your experience of care in order to make sure that the account matches your experience.

These are the only things that will be asked of you.

RISKS AND BENEFITS: These interviews are not meant to be about experiences that were traumatic or painful, but it is possible that the interview may bring up
traumatic or painful memories. However, the risk of this should be no greater than in any discussion of your experience as a provider or consumer of mental health care.

Participation in this study will help people who are working to improve the quality of mental health care. By sharing your experiences, you will add to our understanding of what it is like to work or receive services in the field. This information helps us to understand the effects of changes in mental health care.

COMPENSATION: Mental health care provider participants will not be compensated, as interviews will be completed during work hours. Consumer participants will be offered a $10 Dunkin Donuts gift card.

CONFIDENTIALITY: Your name will never appear on any of the research documents nor in any part of the final paper. You will be referred to by a pseudonym. If you mention anyone else’s name during the interview, they will also be referred to by a pseudonym in all written documents. Any other identifying material will be deleted or disguised.

The researcher will use audio recordings only for the purpose of transcribing the interview. All audio recordings, written materials, and consent forms will be stored in a locked file in the researcher's home. Recordings and consent forms will be destroyed within one year of the paper presentation.

RIGHT TO WITHDRAW: You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time.

SUMMARY OF RESULTS: A summary of the results of this paper will be given to you, at no cost, upon request.

VOLUNTARY CONSENT: I have read the above statements and understand what is being asked of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that if I have any further questions about my participation in this study, I may call Sarah Hamilton, M.A. (XXX-XXX-XXXX), Dr. Russell Walsh (412-396-5067), or Dr. Linda Goodfellow, Chair of the Duquesne University Institutional Review Board (412-396-6326).

_________________________________________  __________________
Participant's Signature                      Date

_________________________________________  __________________
Researcher's Signature                      Date
Appendix C: Informed Consent Assessment

UNDERSTANDING MY PARTICIPATION IN A RESEARCH STUDY
DUQUESNE UNIVERSITY
Project Title: Clients’ and Providers’ Experiences of Recovery Oriented Care for Schizophrenia: A Qualitative Research Study
Principal Investigator: Sarah Hamilton, M.A.

I am going to ask you some questions about what I’ve told you today because I want to be sure that I have done a good job of explaining our study to you. If you would like more information, we can talk about the study some more either now or later.

1) Is this research study to help improve how mental health care services are delivered to the people they serve? (Yes)

2) Was one of the purposes of this interview to tell you about the risks and benefits of this study so that you can make an informed choice about whether or not you want to participate? (Yes)

3) Do you have to participate in this study if you want to get or keep getting services? (No)

4) Can you drop out of this study at any time? (Yes)

5) What would happen to your services if you dropped out of the study? (Nothing)

6) If you decide to stop participating, how would you let us know? (Talk to you)

7) If you decide to participate, you will be interviewed once. What kinds of things will you be asked about? (My experiences in mental health care, etc.)

8) If you decide to participate, some time after your interview, you will be asked to read through a written account of what you told me about your experiences. Why are we asking you to read this account? (To make sure that it matches my experience).

9) Can you stop the interview at any time if you feel uncomfortable? (Yes)

10) What does it mean that information about you will be kept “confidential” when I talk or write about this study? (Any of the following: it’s private, you can’t tell anyone my answers, what gets said here stays here)

Thank you!

(Potential participants must provide correct answers to all ten of the questions above in order to demonstrate their understanding of the study requirements and parameters prior to giving informed consent for participation.)
Appendix D: Semi-Structured Interview Questions

Clients’ and Providers’ Experiences of Recovery-Oriented Care for Schizophrenia: A Qualitative Research Study

Interview Questions

Interview Questions for Mental Health Consumer Participants

Some of the questions may not be asked, additional questions or prompts may be used, and the order of questions may vary depending on the flow and content of the individual interview.

1. What kind of mental health care do you receive these days?

Probes: Do you meet with any staff at the mental health center? What kinds of things do you talk about? What do you do in this program? What's that like?

2. I understand that you’ve been using mental health care for some time now. How does the care you’re getting now feel different from your experiences in the past?

Probes: Are there any ways in which the care you are receiving today is different from the treatment you received before?

3. What differences have you noticed between the providers or professionals you work with now as compared to those you worked with before?

Probes: Do people treat you any differently today from how they treated you in the past?

4. How does participating in this program/coming to this clinic make you feel about yourself?

5. How does participating in this program/coming to this clinic make you feel about the world around you?

Demographic Questions for Mental Health Consumer Participants

1. How old are you?

2. How old were you when you began receiving treatment for mental illness?

3. How many different treatment programs have you been involved in?
Appendix E: Interview Transcripts

Participant 1: Thomas

**Interviewer** (00:01:22): So, um, what kind of mental health care do you receive these days?

**P1** (00:01:29): I have a, ah um, a PRN psychiatric nurse that prescribes my med--medication, psychiatric medication. And, um, I'm a member of a clubhouse? And I am the, uh, chef of that clubhouse.

**Interviewer** (00:01:43): Ah, that's very cool.

**P1** (00:01:45): So I help run the culinary unit.

**Interviewer** (00:01:45): Wow.

**P1** (00:01:49): And, uh, they--they--they're based on the recovery model based on Fountain House.

**Interviewer** (00:01:54): And, uh, how long have you been involved with that clubhouse?

**P1** (00:01:55): Um, officially since '98, but before that maybe '95, 1995.

**Interviewer** (00:02:00): So quite some time?

**P1** (00:02:01): Yes.

**Interviewer** (00:02:03): Yeah. And have you worked with that, uh, the nurse you mentioned, have you worked with her for some time?

**P1** (00:02:10): Yes, I have.

**Interviewer** (00:02:12): Okay. Do you know approximately how long?

**P1** (00:02:15): Oh, gosh. Quite a while.

**Interviewer** (00:02:16): [Laughs].

**P1** (00:02:20): Um, I--I would say probably 15 years or so.

**Interviewer** (00:02:22): That is quite a while.

**P1** (00:02:23): Yeah.

**Interviewer** (00:02:24): And so what kinds of things will you talk to her about when you guys meet?
P1 (00:02:28): Well, the, uh, the--the medication review lasts about 15 minutes.

Interviewer (00:02:31): Okay.

P1 (00:02:32): And when she--that--they--she goes over my, um, symptoms and how I'm--how I'm doing and sometimes I talk to her about a problem that I'm having. But, the, uh, it usually is limited to 15 minutes and then she'll say, "Well, okay, we'll continue with the, uh, medi--medications the same, don't make any changes."

Interviewer (00:02:53): Mm. And at the clubhouse, is there anyone you speak with regularly? About, you know, anything that's going on with you?

P1 (00:03:00): I have a supervisor.

Interviewer (00:03:01): Oh, okay.

P1 (00:03:02): And I also--the director, sometimes I talk to--to the director.

Interviewer (00:03:03): Okay. And what kinds of things will you talk about with them?

P1 (00:03:06): Usually, it has to do with work.

Interviewer (00:03:10): Ah.

P1 (00:03:11): But, if--if I do have some kind of problem, sometimes I will talk to my supervisor.

Interviewer (00:03:16): Uh huh. And--and is--are they able to talk with you in a way that feels helpful?

P1 (00:03:24): Yes, but I think the emphasis of the clubhouse is on work readiness, so it's not so much, um, discussing--they don't really have time to discuss, um, my personal problems. So, if I had to do that, um, I used to have a therapist, and sometimes I talked to the therapist, but, uh, right now, um, there isn't really anybody that I could talk to in--in depth about any kind of problem that I'm having. In terms--personal problem, if it was a work related problem, then I'd be able to talk to them.

Interviewer (00:04:00): That's very covered. And, oh, when did you stop seeing the therapist?

P1 (00:04:04): Um, probably about 15 years ago also.

Interviewer (00:04:08): So, quite some time.

P1 (00:04:09): Yeah.
Interviewer (00:04:12): [Pause] Wh--how has it been to not have that conversation as part of your daily life or as part of your, sort of, care?

P1 (00:04:22): [Pause] Um, for the most part I [pause] I am okay with it.

Interviewer (00:04:27): Mm. [Pause] Is there anything that you miss about that relationship?

P1 (00:04:33): Well, right now I'm trying to, um, set up, um, trying to understand my, uh, plans for, uh, es--estate planning. My parents are aging. And, I'm trying to, uh, come up with a plan that will allow me to, uh, keep my entitlements and, uh, keep my, um, in--inheritance or anything else that comes along. I'd like to live where I'm living now and so I--uh--I would talk about that with them, instead what I think I'll probably do is talk to a lawyer.

Interviewer (00:05:06): Mkay [sic]. And, um, at--where is it that you're currently living?

P1 (00:05:10): With my parents.

Interviewer (00:05:11): Oh, okay. So you'd like to stay in that home.

P1 (00:05:14): Yes.

Interviewer (00:05:15): A--and, have you been living with your parents kind of all along?

P1 (00:05:19): Yes.

Interviewer (00:05:20) So that's very familiar and comfortable.

P1 (00:05:22): Yes.

Interviewer (00:05:23): Yeah. Well, it sounds like a lawyer would be a good person to speak to about that.

P1 (00:05:28): I do have also, I forgot to mention, I have--I used to have what they call a case manager.

Interviewer (00:05:33): Uh huh.

P1 (00:05:35): Now, they have something called community support program.

Interviewer (00:05:37): Okay. Yeah.

P1 (00:05:37): So, um, they don't really have case managers the same way they did before, but sometimes if I have as--uh--uh--important question I can contact that person.

Interviewer (00:05:46): Can you tell me a little bit more about what those services were like? That you get through that?
P1 (00:05:50): Um, well, when it was case management, uh, what they would do--what--uh--this person did is [sic] set me up with my entitlements. And refer me--make rec--recommendations about different people that I could meet--need to see, like, uh, sh--she, uh, set me up with a dentist, a good dentist that takes Medicaid.

Interviewer (00:06:08): Yeah.

P1 (00:06:10): Um, so sh-she helps me with, um, getting connected with services.

Interviewer (00:06:14): Mhm. [Pause] So that--that is something that you still get now or that's how it was in the past?

P1 (00:06:20): That's how it was in the past.

Interviewer (00:06:21): Okay. And so--so now, how would you navigate some of that?

P1 (00:06:25): Um, I could try contacting the same person again or I might be, um, referred to a-
-an agency to contact [pause] to, uh, ask directly. Uh, ask the question directly to them.

Interviewer (00:06:41): Yeah. [Pause] Does it feel, um, let's see, it will take a minute for me to formulate my--my response. Um, [pause] h--how does it feel to have less, um, perhaps direct contact in that way?

P1 (00:07:03): Um, [pause] I think that I don't--I don't need as much contact with them as--as I did in the past. Um, so it--it--so it feels--s--sort of--it feels good in a way to be self-sufficient, um, but at the same time, I think that once in a while I might run into a problem that I can't handle and that I might want to discuss it with someone.

Interviewer (00:07:28): Yeah. [Pause] And when those times arise [pause] who might you look to to discuss those problems?

P1 (00:07:37): Probably my parents.

Interviewer (00:07:39): Ah, okay.

P1 (00:07:40): Or I might, uh--do--a look on the Internet, and then try to find out a number--phone number or email address and contact someone. I do, uh, through my, uh, former case manager, I do have someone in the Department of Social Services that I sometimes talk to, but she's very hard to get ahold of.

Interviewer (00:07:55): Mm, I imagine.

P1 (00:07:58): Yeah.

Interviewer (00:07:59): So--so, it's a little--it sounds like--it's a little less clear [pause] who to
contact in moments of need, is that--is that . . .

**P1** (00:08:05): I'd say so.

**Interviewer** (00:08:06): Yeah? Um, but that it--that often feels, sort of oh--it feels like that's okay, mostly . . .

**P1** (00:08:14): Most of the time.

**Interviewer** (00:08:16) Yeah, but then when that--when you are in moment of need, that's tougher.

**P1** (00:08:19): Yeah, yes.

**Interviewer** (00:08:20): And, um, s--you mention your parents passing, um, [pause] do--how do you anticipate that will change the support you have?

**P1** (00:08:34): Um, [pause] it's going to be a shock and it's going to be a big change . . .

**Interviewer** (00:08:41): Yeah.

**P1** (00:08:42): And I--and I dunno [sic] how I'm going to handle it. I could have a relapse.

**Interviewer** (00:08:44): Well, it--it’s diff--difficult for all of us to face something like that. So, I'm--what I hear is that that's sort of a--a moment that causes you some anxiety.

**P1** (00:08:55): A great deal, yeah.

**Interviewer** (00:08:57): [Pause] And for--for a number of reasons, all very understandable. Um, how--how do you think you might find some stuff to support yourself as you move towards that phase of life?

**P1** (00:09:12): Well, what I'd like to do is, um, set up this--uh--plan the estate so that I can have- -um--keep the inheritance and keep my entitlements . . .

**Interviewer** (00:09:22): Yeah.

**P1** (00:09:24): And then have a--uh system that--there's a--there's a firm that is sort of like a firm for people--for seniors and also for the disabled. And, um, they have a lawyer, they have, um, they have people that do estate planning, they have--they cover just about every aspect of that.

**Interviewer** (00:09:44): Okay.

**P1** (00:09:45): And, uh, if I could get, uh, connected with them I think that they could probably help me manage my finances and also advise me in times where I might come into some sort of legal trouble or something.
Interviewer (00:09:57): Ah, yes. That--that makes a lot of sense.

P1 (00:10:00): And that happens a lot with people, uh, dis--disabled persons, they get into all kinds of legal problems [chuckle].

Interviewer (00:10:06): So--well, it's all very convoluted and difficult to navigate, yeah, for--for all of us, and certainly more so when you have a--extra needs that are, sort of, worked in. So, um, I--I know you've been using, uh, mental health care in some form for quite some time now . . .

P1 (00:10:28): Mhm. Yes.

Interviewer (00:10:29): Um. How does the care you're getting now feel different from the care you received in the past?

P1 (00:10:36): I am, uh, more independent now. [Pause] Um, in the past, um, I was dealing more with symptoms and just trying to function and I think that pretty much I, uh, moved beyond that. I went to--back to school and, uh, got--went, uh, got a--a culinary arts certificate and got involved with cooking and I found that the, uh, work, the cooking and doing work was not only, you know, financially lucrative, but it also helped me, uh, in terms of my symptoms, keeping busy and not thinking about my problems so much.

Interviewer (00:11:14): Mm, definitely. And so, um, so part of the difference I'm hearing you say is that your need changed. Do you think there was also a difference in how, um, help was offered?

P1 (00:11:32): [Deep breath] Let's see. [Pause]

Interviewer (00:11:36): Or perhaps, um, another way of saying it is, what were some of the differences of what was available to you in terms of care?

P1 (00:11:43): Well, I started out in the partial hospital program. So, um, they had a psychiatrist there and he would prescribe medication and then I would go to what are called groups, activities, within the building, and, um, that--that was sort of, um, a place where--you c--i--it's sort of like a hospital, sort of.

Interviewer (00:12:08): Yeah.

P1 (00:12:09): Where you're kind of recuperating, and then, I moved beyond that, to the Clubhouse. Well, the Clubhouse is the Fountain House model, I believe, recovery model, and it's--and it's about, um, work readiness, and, um, being responsible, and being independent.

Interviewer (00:12:24): And is everyone in the Clubhouse, are they all peers? Or are there some staff who are, sort of, coming in from outside?

P1 (00:12:31): Oh, it's def--they definitely have, uh, staff there.
Interviewer (00:12:34): As well.

P1 (00:12:35): Yes.

Interviewer (00:12:35): And, um, so how are your interactions with staff there different than your interactions were [sic] in the--your partial hospitalization?

P1 (00:12:46): In the partial hospital, um, I--I was more a patient. At the Clubhouse, I'm an employee.

Interviewer (00:12:54): A--and this--this is a tricky question, so bear with me. Um, h--how does one feel as opposed to the other?

P1 (00:13:03): Um, at the time of partial hospital, I think I needed it. And, I think that, um, well wh--what really helped there was when they came out with, um, Zyprexa. And, um, that's--that was kind of the turning point for me, because before that the medications that I took had so many side effects that I wasn't really doing very well, mentally.

Interviewer (00:13:29): Yeah.

P1 (00:13:30): Um, so, I--I needed that. And then when I moved on to the Clubhouse, um, I was glad to, uh, be a--a paid employee and earn some more money and be more independent. So that feels good, too.

Interviewer (00:13:45): Yeah, yeah. [Pause] Were there, or are there, any differences in how the staff in each of those places interacted with you, or interact with you now?

P1 (00:14:02): Some of them--some of the people that were at partial hospital, moved over to the Clubhouse.

Interviewer (00:14:08): Oh, okay.

P1 (00:14:10): I think the director was the same person. Um, so, um, I sort of had to prove to this person that I was--that I was ready to go back to work. So, um, when I was at the partial hospital, I had to prove to this person that I was ready to go back to work and, um, so your--your question was, how--how--how did they, how--how did they, um, treat me? Or how did they--how do I interact with them differently?

Interviewer (00:14:39): Yeah, yeah.

P1 (00:14:49): [Pause] I'm expected to be a, uh, competent employee at the Clubhouse.

Interviewer (00:14:55): So, there is, um, there is an expectation of your showing up and being, uh, capable, and sort of able to engage with the work.
**P1 (00:15:06):** Yes, definitely.

**Interviewer (00:15:08):** Are there other expectations beyond those?

**P1 (00:15:10):** I'm--I'm what they call peer support staff.

**Interviewer (00:15:12):** Okay.

**P1 (00:15:13):** So, um, I am a member of the Clubhouse, but I'm--I'm also first and foremost an employee of the agency.

**Interviewer (00:15:19):** Uh huh.

**P1 (00:15:21):** So, it was a big transition to go from "patient" to "employee."

**Interviewer (00:15:24):** Yeah. [Laughs] Yeah. Is there an expectation of you, um, providing support to peers?

**P1 (00:15:33):** No, but I--I do--d--I do, um, talk to them a lot in the course of the work, because we have people sign up to volunteer for diff--the various units. I'm in the culinary unit, so they will sign up for a task in the culinary unit, they don't get paid for it. They volunteer, and, um, they have to be shown what to do and I kind of, like, supervise them. So, in the process of working with them, sometimes they will talk to me about problems that they have and I will discuss it with them, but I'm not really supposed to get--do too much of that, because it's distracting from the work that I'm supposed to do . . .

**Interviewer (00:16:07):** I see.

**P1 (00:16:08):** We're preparing a lunch each day.

**Interviewer (00:16:09):** Yeah, yeah.

**P1 (00:16:12):** And, there's a lot other responsibilities that I have just b--besides preparing the lunch, because I plan the menus and I do the shopping, and--and, um, uh, when we have parties, I help plan the parties, and . . .

**Interviewer (00:16:22):** So there's a lot of work involved.

**P1 (00:16:23):** There's a lot of work involved.

**Interviewer (00:16:26):** And h--how many people are you preparing food for each day?

**P1 (00:16:27):** Um, I--I--typically around, um, it used to be 24 a day, now it's kinda [sic] dropped off some days. Um, but, uh, up to like 24 or 30 people.

**Interviewer (00:16:40):** So, yeah, quite a--quite a number. Quite a lot of work. And, um, are the-
-the people who come in who you're sort of supervising, are they in the same, um, uh, s--sort of area of recovery or are they in a different place in their recovery?

**P1** (00:16:57): I think that it's--there's a wide range of people.

**Interviewer** (00:17:01): Okay.

**P1** (00:17:02): Some of them are--are n--are more deilitated, some of them are--are--actually went back to work and are working now.
So it's a wide range.

**Interviewer** (00:17:12): Okay, so you get sort of a full spectrum of experience there.

**P1** (00:17:14): Yeah. Yes.

**Interviewer** (00:17:15): And, um, [clears throat] you--so you said that the director moved over from the--the partial hospitalization and--and is now a--at the Clubhouse?

**P1** (00:17:25): She--she was. Uh, she retired.

**Interviewer** (00:17:27): Oh, okay. So . . .

**P1** (00:17:28): So now there's a new director.

**Interviewer** (00:17:29): A new person. Well, s--so, um, that--I g--that brings up something interesting. Do you--have--are there any differences or what are the differences between how the director who knew you from partial and the one who doesn't? Is there any difference in how they interact with you?

**P1** (00:17:48): Yes. [Sigh] Um, the former director was part of, um, an organization, I'm trying to think of the name of it, uh, Psycho-Social Rehab or something like that? Which made me think that she was more geared toward the rehabilitation model. The new director is definitely recovery model-oriented.

**Interviewer** (00:18:11): Okay.

**P1** (00:18:13): So, the--the old director was sort of, uh, a person that was sort of, um, she--sh--she liked to be very much involved in running things and directing people.

**Interviewer** (00:18:26): I see.

**P1** (00:18:28): Um, the new director is more where she just sits back and she lets you t--take over.

**Interviewer** (00:18:34): Okay.
P1 (00:18:36): So--so, that's basically the difference.

Interviewer (00:18:38): So, the new one is more hands off and allows . . .

P1 (00:18:40): Yeah.

Interviewer (00:18:42): You to, um, s--sort of guide how you want it to go.

P1 (00:18:44): Yes. And then she relies on my supervisor if I have any problems or questions, then she expects me--she says--she wants me to go to my supervisor, my immediate supervisor for that.

Interviewer (00:18:56): And is your supervisor also someone in recovery or is the supervisor, uh, outside staff?

P1 (00:19:02): Um, outside staff.

Interviewer (00:19:03): Okay. So, [clears throat] what were any [sic] other differences between them?

P1 (00:19:10): Personality.

Interviewer (00:19:11): I--in what w--can you tell me more about that?

P1 (00:19:15): The personality of the first director was more, um, [pause] let’s see, [pause] dictatorial.


P1 (00:19:26): Um, sh--she--she, um, she was more, um, emotional, hot--hot tempered sort of, she could get very angry.

Interviewer (00:19:36): And, h--how did that--how did that manifest, how did that look?

P1 (00:19:42): Um, [pause] well, she had a way of--of making me, um, uncomfortable, when she found--when I did something wrong, she made me very uncomfortable.

Interviewer (00:19:53): Oh, wh--uh--uh--in what ways?

P1 (00:19:57): Well, um, [pause] she, uh, raised her voice, she, uh, had an angry tone. Um, [pause] and, she just had a way of making me feel, um, small, I guess you could say.

Interviewer (00:20:16): And that is not something that you experience with the new director.

P1 (00:20:19): Well, the new director is sort of like that too, but in a different way.
Interviewer (00:20:23): [Laughs].

P1 (00:20:24): She--she--she's, uh, she's--she's a--she's a manager, what I call a "manager-type," there were both "manager-types."

Interviewer (00:20:31): Uh, huh.

P1 (00:20:32): And, the second one is--I think she used to work at another clubhouse.

Interviewer (00:20:36): Okay. Yeah.

P1 (00:20:39): And, so, um, she also has a--she has a s--a--two positions in the agency, she's not only a director of the Clubhouse, she's also, um, employment, uh, support.

Interviewer (00:20:49): Okay.

P1 (00:20:50): So, I think she helps people find jobs. So, um, she--she is, what I would call a "manager-type," so that, you know, she--she definitely wants to keep things running smoothly and she wants to be authoritative, because if you don't, um, sometimes the people that I work with, the, you know, the clients, and different people that--there, they will--they will disregard what you tell them, unless you tell them in an authoritative way.

Interviewer (00:21:18): Mhm, [laughs] sure. A--an--and the other staff who are now at the Clubhouse, um, how are those other staff different from the staff who you were around at the hospital?

P1 (00:21:34): [Deep breath] [Pause] They're pretty--they're--they're very similar.

Interviewer (00:21:50): Okay.

P1 (00:21:51): In the way that they approach things.

Interviewer (00:21:53): How are they? So, what are the similarities?

P1 (00:21:56): Um, they know how to talk to people with disabilities. And, uh . . .

Interviewer (00:22:04): Can you give me an example of--of what--how that looks or what that might be?

P1 (00:22:10): Well, one--one piece of it is the disciplinary piece, because sometimes the--we--for example, um, we have people that, um, do th--are--aren't supposed to certain things, like, uh, they will, um, there's a designated smoking area. And sometimes they won't, uh, use it and they'll do different things, they'll throw their cigarette butts on the ground, and so they have to say--like the director will say, "Well, you know, if you--if you put your cigarette butts--if you throw them on the floor or you throw them near the building, the building could catch fire."
Interviewer (00:22:45): Right [laughs].

P1 (00:22:46): So, um, they have to be told, 'cus [sic] there--there's a wide spectrum of people in different places in their recovery. And they have to sort of be, um, disciplined somewhat, um, so they have--they have to be able to handle that type of person. That type of client. You know, to kind of, like, direct them and help them--show them what to do. And, also, um, they have to have a patient side when they're trying teach something to a--a client, they have to be very patient with them and kind of work with them and, uh, help them, you know, supervise and help them--sh--show them what to do.

Interviewer (00:23:26): And are they able to be patient in those moments?

P1 (00:23:32): Um, they are w-- [pause] yes.

Interviewer (00:23:37): [laughs].

P1 (00:23:39): With me not so much, but with them they are. They expect more out of me because I'm an employee.

Interviewer (00:23:43): Ah, I see. So, your s--your different position in the Clubhouse means that, sort of, their interactions with you look different.

P1 (00:23:51): Yes.

Interviewer (00:23:53): Ah-- [pause] do you think--do you feel you are treated more as an employee than as a client?

P1 (00:24:00): Yes.

Interviewer (00:24:02): Okay. So, there--in many ways--probably feels like a big difference.

P1 (00:24:06): Yes.

Interviewer (00:24:08): Um, let's see, uh, wh--what other differences have you noticed, um, between the providers or professionals you work with now and those in the past?

P1 (00:24:28): [Pause] Well, the psychiatrist at partial hospital, um, he was very stern, he came from the prison system. And, um, he had a bad temper. So, um, it was hard working with him an- -and also--well one of the things that came up when I was in partial hospital was that they put me on some medications that didn't agree with me. And, um, when I asked to be changed to something else, they didn't--they didn't, uh, listen to what I said.

Interviewer (00:24:55): They weren't respectful of your request.

P1 (00:24:57): Right. Th--they disregarded my input, so, um, it--it--I s--struggled for a long time with, um, side effects from the medications. Um, in the new pl--in the--with my new, uh,
psychiatric nurse, she listens very carefully to what I say, and luckily Zyprexa came out so the medication--that medi--medication seems to agree with me, pretty much.

**Interviewer** (00:25:20): So, one major difference is that your input was not taken up in--with the psychiatrist, and with the nurse, you find it is.

**P1** (00:25:29): Yes. Also, I think that sometimes the, uh, other staff at the--at the partial hospital did not, uh, listen to, uh, my, um, needs or requests, advice, um, um, for example, there was one time there where I, um, [pause] was talking to myself, I was hearing voices, and I was talking to myself. And they interpreted that as me not being able to drive home, so they took my keys away. And, um, the, uh, the, um, I--I--I want--I asked for the keys back and they would--they took away my--they took the keys away and they wouldn't give them back and I told them that I was going to go to the police station and complain that--ask the police to have them give my keys back. What instead happened is that I got taken to, uh, a, uh, hospital - psych hospital - so, that's one example. It was kind of a dark time for me, the partial hospital, it was--it was rough. Um, and we were also, uh, we did manual labor, um, it was--there were chores there also, so, the chores, I guess, were probably designed to help you in your recovery, but, um, it--it was difficult.

**Interviewer** (00:26:50): What kind of chores were they?

**P1** (00:26:52): Sweeping the floor, um, they had a, um, they have other things too. What did they have? Uh, mostly--I'm trying to think--uh--sweep-sweeping the floor, um, [pause] they had a--a culinary block there, a culinary unit, that's where I first got involved with cooking. And, um, [sniff] so, there were chores within there [sic] where you--you would be assigned to prepare a certain dish, certain, uh, p--certain food. Um, I'm trying to think of what else were there chores. I think we--we had a, um, we had a--a--I think what was called a "consumer council," we had like a president, a vice-president, stuff like that. I was, uh, president of the co--of the, uh, uh, hospital for a while - partial hospital - so, I--I would--I would sort of run meetings with the--with the patients there. Clients, I guess they call them more than--more than patients. But, I would run the meetings.

**Interviewer** (00:28:00): Okay.

**P1** (00:28:01): So, um, you asked me what the difference was between the partial hospital and the Clubhouse?

**Interviewer** (00:28:05): Uh, bet--with the staff and the people you worked with.

**P1** (00:28:09): With the staff.

**Interviewer** (00:28:10): Yeah.

**P1** (00:28:11): Um, [pause] I think--I think that the staff at the Clubhouse are [pause] better suited to the Clubhouse and the people at the partial hospital, some of them were not well suited for, uh, mental health, uh, treatment. Um.
Interviewer (00:28:37): What--what made them less suited?

P1 (00:28:40): Um, they--they--they didn't--they weren't, uh, sensitive to the, uh, s--uh--clients--sensitive to the clients.

Interviewer (00:28:52): And, what makes the people at the Clubhouse more suited?

P1 (00:28:57): They're more sensitive to our needs and so forth. Although, um, in both places there is kind of a dictatorial side to it. Um, because, like I said before, um, people--some of the--some of the members will misbehave. And, uh, w--they set up--wh--a, uh, they set up a, uh, what's it called, um, a r--rules committee. So they have what they call a "matrix of rules." So, a--at some point - this is in the past, I don't think they have this anymore - but they had a system where if you broke a certain rule, then there was a certain consequence. And, the first consequence might be suspension for a day. And then maybe it would be a week or a month, and then finally, the final consequence would be total, you know, permanent suspension.

Interviewer (00:29:49): From the program and stuff.

P1 (00:29:50): From the program. So, um, they did that for a while, but then somehow they decided that they wanted to try this new system where the person would sort of, like, have a, uh, somebody counsel them about the problem - this is s--a recent development - they're--coun--being counseled about the problem, and, um, they're shown ways that they could do things differently, so that they wouldn't, uh, cause a problem.

Interviewer (00:30:21): How has that changed how people, you know, um, follow the rules or how--how they have problems?

P1 (00:30:32): I don't know yet because it's a rec--it--they just changed over to the new system. So . . .

Interviewer (00:30:37): Very recent.

P1 (00:30:38): Very recently, so, I don't--I don't know.

Interviewer (00:30:42): Uh, do you have any guesses about what will be different?

P1 (00:30:47): [Pause] It's hard to say. I think there's a few people there that maybe not--will not respond. But, uh, for the most part I think that, uh, there's--there's a lot of women in the program and I think that the women might respond better, um. Um, I--I think--I think that, um, I have a feeling that it--if--and just a--just a hunch that it--it probably, uh, will make some people more comfortable.

Interviewer (00:31:17): Hm. [Pause] Wh--what about it do you think will make them more comfortable?

P1 (00:31:22): The fact that there--there isn't a punishment for their behavior. Instead of a
punishment, they are actually guided as to--or advised as to what to do.

**Interviewer** (00:31:31): Yeah. I could--I could see why that would be different.

**P1** (00:31:36): Mhm.

**Interviewer** (00:31:37): And, uh, I--I don't think I asked you, um, when--wh--when--what year or how old were you when you were in the hospital--when you were in the hospitalization [sic] program?

**P1** (00:31:47): Um, I started around 1989.

**Interviewer** (00:31:51): 1989. And s--and then--it's been about--what you said--about 15 years since you were in the Clubhouse [sic].

**P1** (00:31:57): Mm, yeah. I--I got out of partial hospital--I--I s--I think I started going to cooking school around '93, so from '89 to '93, I was at the partial hospital and then '93-'94, I was, um, going to cooking school and also I was working part time with my father in--in electronics, 'cus I have an engineering degree. I have a bachelors of science in electrical engineering, so I was working as a technician--electronics technician for the same company that my father worked for. I probably could have gone there, uh, f--pa--uh, full time and worked there full time, but they went out--they--they went out of business. They--they f--they kind of--I think their--they were bought out by another company and then they moved out of state.

**Interviewer** (00:32:44): But you've been cooking now for quite a long time.

**P1** (00:32:46): Yeah. So, around '95 or so, I was--I was there on stipend, at the Clubhouse. And, um, then in '98, I think that's when I was formally, um, hired as s--staff.

**Interviewer** (00:33:00): I see. All right. And, um, h--how does participating in the Clubhouse, uh, make you feel about yourself? I know that's a big question, but [sic].

**P1** (00:33:12): Well, I feel--I feel like I have a marketable skill as a chef. So, I feel like if I--if something happened, um, or some--some--for some reason the program closed or if I was laid off, or something like that, that I could get work as--as a cook.

**Interviewer** (00:33:30): So, there's a sense of stability and security?

**P1** (00:33:32): Yes.

**Interviewer** (00:33:34): Are there, uh . . .

**P1** (00:33:36): Oh, I can say something else, too. I like the people that I work with there. Um, I did have some trouble when I was working in--outside of the, uh, agency. Some people--I--I tend to disclose my illness to them and what happened was--is that I--I was, uh, abused because of that. Uh, people actually, kind of, um, for some reason they--they put me down, because I was--I
had a disability.

**Interviewer** (00:34:07): Yeah. And--and they don't do that in the Clubhouse.  
**P1** (00:34:10): No, it's a very safe place, it's--for the most part, people understand where you're coming from.

**Interviewer** (00:34:17): And do the staff, or the providers and people who you work with, how do they make you feel now?

**P1** (00:34:24): The staff and the providers?

**Interviewer** (00:34:25): Yeah.

**P1** (00:34:29): [Pause] For the most part, um, well, um, I do get a sense from them that--that my disability does limit my--my work ability somewhat.  I--I--I feel like I'm running up--running up against limitations, in terms of like remembering things. So, I have to try to write everything down because, uh, when they give me a lot of information, sometimes I can't remember it all and then sometimes I will forget it, that I had to do certain things. So, when that happens sometimes I--I get criticized, but for the most part, they do a, uh, yearly evaluation of me, and my evaluation was like, near the top, like five was the highest mark and most--a lot of them my--my marks were in the fives or fours.

**Interviewer** (00:35:16): How does it feel to get an evaluation like that?

**P1** (00:35:18): I--I feel good, I--I feel like I'm--I'm doing a good job, however, I do feel somewhat limited by my disability.

**Interviewer** (00:35:25): I see. A--and, w--what could they do that would make you feel that less, do you think? If anything.

**P1** (00:35:39): [Pause] Maybe, n--not be so, uh, judgmental or critical when I make a mistake. But, at the same time, I think they're trying to create an environment where you would--trying to simulate what you what you would f--experience in the community, if you had a job out there.

**Interviewer** (00:35:56): I see. So, it's a little bit of a double bind.

**P1** (00:35:59): Mhm.

**Interviewer** (00:36:00): To keep it professional, they might need to do that, but it certainly doesn't always feel as comforting.

**P1** (00:36:06): Mhm.

**Interviewer** (00:36:07): And, um. How does participating in the Clubhouse make you feel about the world around you, in general?
P1 (00:36:17): Um. [Pause] I--I feel like I'm in a safe place where I am. I feel more secure there. I feel like if I were able--if I were to leave that environment and go out into the community, that I--I might be treated in the same way I was before, where I was sort of, uh--sort of, uh, put down or--or maybe in a--in a situation where, let's say, I had--was having some kind of psychotic symptom that they may not understand what's going on and there--that there might be some kind of, uh, serious consequence to that.

Interviewer (00:36:55): I see. So, it changes how it feels in that space, but once you go outside of the Clubhouse, it doesn't necessarily change that.

P1 (00:37:05): No. Well, in terms of my work readiness, I think my work readiness is better, I think I can work better now and my symptoms are more under control. So, from that standpoint, I think that I'm--I'm more ready for work, and that's basically the community interaction that I think of as the workspace.

Interviewer (00:37:25): Yeah. Does that idea make you feel more confident?

P1 (00:37:28): Yes.

Interviewer (00:37:30): Yeah. Um, but, so in work it feel--you feel more confident, but perhaps not, um, not just in engaging in the community in other ways.

P1 (00:37:42): Um, can you give me an example?

Interviewer (00:37:44): Yeah, um, so--so, for ins--do you--do you attend any churches or . . .

P1 (00:37:50): Yes, I'm--I'm, uh, involved with my, uh, Catholic Church.

Interviewer (00:37:54): Okay.

P1 (00:37:55): I'm deeply involved in my church community and also in a local mental health advocacy organization

Interviewer (00:38:18): Wow.

P1 (00:38:19): So, um, that--that was--that was really good, that--they gave me a lot of confidence, too.

Interviewer (00:38:25): Yeah. So, has the Clubhouse, do you think, um, has the Clubhouse changed or how has the Clubhouse changed, how you feel about things like that? Or how you feel about engaging in the church?

P1 (00:38:49): [Pause] I think that my confidence comes from within myself. Um, I don't think that the program gave me confidence so much, but I think that the program gave me stability.

Interviewer (00:39:03): Yeah. And, um, a certain sense of reliability, that it's something that's
there that you can always go to?


Interviewer (00:39:13): Okay.

P1 (00:39:15): Yeah, I--I had been, uh, laid off from a number of jobs prior to that.

Interviewer (00:39:18): I see.

P1 (00:39:19): When I tried to work as an engineer.

Interviewer (00:39:21): Yeah.

P1 (00:39:22): Um, I--I--I--I worked--I was hired, uh, by a company right out of college and I--my father and sister both worked there also. And, um, I had a nervous breakdown while I was there. So, that's when I was hospitalized and then I saw the doctor for a while, the psychiatrist that--at the hospital. And then, I tried to get back into engineering, I--I actually, uh, had a--a Korea neurosurgeon, acupuncturist, psychiatrist. He was--he gave me acupuncture. And, um, I tried--I--I felt like I was well enough to work as an engineer. I worked for a company, uh, I was on--I was on probation--a probation period, they were trying me out, and at the end of that period, I didn't, um, [pause] live up to their expectations, so I was laid off. So, um, I was coming from a place, before the Clubhouse, I was coming from a place where I felt like I wasn't succeeding in--in working--my work.

Interviewer (00:40:26): Yeah. So--so, that's one of the major offerings of the Clubhouse then, is something that is, sort of, more stable and that you can rely on. Is there anything else that you'd like to share with me about your care or your experiences?

P1 (00:40:53): [Pause] Yes. Um, [pause] I work--my--my cul--the culinary unit program has a very tight budget. And, we get a lot of food from a place where you can--it's like a co-op sort of.

Interviewer (00:41:14): Oh, okay.

P1 (00:41:15): And, um, they--what--what happens is, is that I think different restaurants and different, maybe, supermarkets, they donate food to them, ex--surplus foods or foods that they w--don't want.

Interviewer (00:41:35): Yeah.

P1 (00:41:36): And we get it for a reduced price, sometimes for free. Um, the food that we get, I don't feel is healthy, but I think there's--I--I'm--I'm kind of a vegetarian myself, so it's kind of strange being a chef as a vegetarian, but--they're--it seems to me, they're--they're more interested in, like, meat and so I--we serve a lot of meat. And, um, I feel like the meals that I'm preparing are not really the healthiest meals, and I feel like, that the food aspect, what you take into your body has a lot to do with how much you recover.
Interviewer (00:42:12): Sure.

P1 (00:42:13): So, um, I think that what we don't really get as man--as much fresh vegetables as I would like, and I think that we have to cu--I have to really cut a lot of corners when I'm preparing the lunch. So, I--I feel like I am feeding them, but a--at the same time I--I feel guilty that I'm not feeding them they way I would like them to be fed.

Interviewer (00:42:34): It doesn't necessarily live up to your ideal of what you would offer.

P1 (00:42:38): Mhm, yes.

Interviewer (00:42:39): I see, well, it's, uh, impressive and wonderful that you're able to--to feed that many people and do that work regardless. But, I can understand your desire to--to provide even more. Um, I--so I just have a few, sort of, questions about, um, uh--s--concrete questions about you to wind up. Which--uh, how old are you now?

P1 (00:43:07): Fifty-five.

Interviewer (00:43:08): Fifty-five. And how old were you when you began receiving treatment?

P1 (00:43:13): The first--my first hospitalization?

Interviewer (00:43:15): Yeah.

P1 (00:43:16): I was twenty-three when I was first hospitalized.

Interviewer (00:43:18): Okay, and is--was that in the partial hospitalization or a different place?

P1 (00:43:22): It was at the same place.

Interviewer (00:43:24): Okay. And, um, do you know how many different treatment programs you've been involved in?

P1 (00:43:31): Let me see, there was Hartford Hospital, and then I saw the acupuncturist for a while, that was two, and then, this, the agency where I'm at now is three, so I think three.

Interviewer (00:43:43): Three total?

P1 (00:43:44): Yeah.

Interviewer (00:43:44): Okay.

P1 (00:43:45): Oh, also there was a private psychiatrist that the company where I worked for, when I had the nervous breakdown in '83, they sent me to a private psychiatrist.
Interviewer (00:43:54): I see.

P1 (00:43:55): So that's maybe four.

Interviewer (00:43:56): Okay. All right, um, well th--those are the questions I have for you. Thank you so much for, uh, for answering all of those.

P1 (00:44:04): I hope I answered your questions adequately.
Participant 2: Leah

Interviewer (00:00:22): So, wh--if we could just start off by you telling me what kind of mental health care you receive these days.

P2 (00:00:23): Okay, um [pause] after a bit of a hiatus of, uh, maybe two to three years, I just reentered therapy.

Interviewer (00:00:34): Okay.

P2 (00:00:35): To, um, because I'm still dealing with residual post-traumatic stress, um, problems and, uh, uh, fear related to a, um, uh, health, um, situations. And, so--and then I also see a psychiatrist, um, out of, uh, town and I will tell you why later on.

Interviewer (00:01:04): I see. And, um--let's see--the therapist, is she connected to a program or independent?

P2 (00:01:12): Independent.

Interviewer (00:01:13): Okay. All right. Um, s--do you--uh, so you've got the psychiatrist out of town and then the therapist. Is there anyone else or is that? Okay. And, um, what kinds of things do you talk about with the therapist?

P2 (00:01:28): Well, I just started again.

Interviewer (00:01:30): Oh, okay, so . . .

P2 (00:01:31): So it's, um, I—I will say I went not knowing if it was gonna be, you know, a good match.

Interviewer (00:01:40): And is it?

P2 (00:01:41): Absolutely. Just a joy.

Interviewer (00:01:41): That's nice.

P2 (00:01:43): And she has a private office, but was on the third floor, so she agreed to see me in an office that she started out in in her home.

Interviewer (00:01:52): Oh, that's so nice.

P2 (00:01:53): So it's more accessible. And she and I are just on the same page. We both love photography, she's got photo--her photographs all around. And, um, just a lot of things that we seem to enjoy, music and things that we both like.

Interviewer (00:02:18): That's wonderful.
P2 (00:02:19): Yeah. So, it's just so, like, so fun and--and she's so, like, non labeling, just kind of, uses--not even, barely--I don't even see the DSM sitting around her office, so. I like that.

Interviewer (00:02:35): So that feels a little bit more welcoming?

P2 (00:02:38): Mhm, mhm.

Interviewer (00:02:39): And, um, when you decided to go--to go back to therapy--or--was--what were the sorts of things that you were hoping to address there?

P2 (00:02:50): As I said, it was--I've had multiple, multiple, multiple, [laughs] uncountable traumas in my life. Sexual and--and, uh, losses and hospitalizations and treatment that was not good and, um, [pause] I've been in two fires. Yeah, so lots of things.

Interviewer (00:03:16): So, it was sort of--of a combination of--of dealing with emotional history and dealing with the experiences you'd had previously in treatment.

P2 (00:03:29): Yeah, 'cus I keep running up against it. I just seem to get over it and then something else comes in my face and brings it up. I have screaming nightmares and I said to my partner, who's very low-keyed about the whole thing, he said--I said, "Honey, do you think I should go see somebody?" He never said yes before and he said, "Yeah, I think so."

Interviewer (00:03:51): It's n--it's wonderful that you had somebody to ask that of, er . . .

P2 (00:03:56): He's wonderful. He's wonderful. Hey, maybe we'll talk about that later, but yes, um, so, um, and I saw--I do have the psychiatrist out of town. She--I only see her like every three months.

Interviewer (00:04:08): Oh, okay. So quite--there's quite a bit of space in between.

P2 (00:04:11): Space, yeah. And I can always call her for s--yeah, I'm not dependent on her or--in anyway. We just get along well and I respect her and she respects me and she's very, um, let's me kind of guide how things are going to go.

Interviewer (00:04:26): Okay. And how long have you been working with her now?

P2 (00:04:30): Um, mmm, since about 2011? [Pause] On and off. All hell broke loose.

Interviewer (00:04:37): Okay, so, on and off for four years?

P2 (00:04:39): All hell broke loose. I was doing really well and [inaudible, 00:04:42] hell broke loose.

Interviewer (00:04:45): Do you want to tell me more about that?

P2 (00:04:46): Yeah, I will. 'Cus that was--that was a precipitating factor in--I mean, I was
thrive when I got hired here. I was not thriving before I got hired at the local mental health advocacy organization, I was beginning to but, um, I'd always had a background in oral history and writing and literature and, uh, social services work, and in just personal interests. And, uh, I had a psychiatrist who I had seen for many, many years. Many years. Many years. And I had trusted him as you--one would, um, and well, this was the days when psychiatrists would spend more time rather than just medication. So, and--it was beginning to shift. Anyway, I completely trusted him and all the sudden he started saying things like--wanted me to call him by his first name and then he would just make little comments like, um, "Why don't you color your hair like all the other women?" And he started getting flirtatious, but I kind of brushed that off, because he was kinda just like a--anyway, long story short, I'll try to be succinct, it's hard, but I'll be succinct as I've gone over this a million times with the team at work and the people there gave me wonderful support. Um, I was home after--I've had four joint replacements and I was having terrible rep—uh, pain after this knee replacement. I was working and--and had very good support at work, I was allowed to work from home when I was able, when I got better enough. And, um, they allowed me to adapt my schedule, et cetera. Um, so, uh, sur--surgeons cut off your pain medicine, uh, and I was in excruciating pain, so he said to me--and he worked at a very highly respected, um, hospital [laughs]. But, um, he saw me there and he star--he said, "I believe in pain control. I really believe in pain control." So, he started coming to my apartment and he--you know, it's very professional; he'd give you the pain meds and dudda dada da. So, when I was able to start walking a little bit, I'd walk him to the door, which was just, you know, it was just on one level and I'd walk him out to the parking lot and he'd give me like a bear hug. Well, the bear hug started getting nuzzle-y. In my neck. And close and pressing. And also became suspicious about the pain medication. And, I won't dis--[pause] evolved. And after a time, I became fully aware, after a lot of god-awful reflection and what the hell do I do and who do I turn to. And, uh, I went to visit my family; I spent most of the time holed up in the--in my room. I was crying and--about things that they didn't know, they didn't know exactly what I was doing then, they thought I was just, you know, reading or something. I mulled it over a lot. And I got enraged. I said, "This is really, really bad." And, uh, I realized I had to do something and I came home and I did have a therapist at the time, thank God almighty a woman, and she supported me and I got support here. And I happened to be in a DBT program at the same hospital simultaneously, 'cus I was starting to slide, but I wasn't identifying exactly what was going on. I went in for the second time and I said in the intake, "Somebody on staff is abusing me. And he's diverting meds." So the next--I thought they were just going to gloss over it. So the next time I came in, the Director of Medicine was there. Or the Director of Something, a bigwig. And I--I thought, well this is interesting, 'cus they usually have a resident or somebody I didn't think much about. He said, "Tell me. Right now. Tell me what is going on." I told him. He said, "You can choose to do one of two things. You can write him a letter and terminate. And we will take over. Or, you can terminate yourself, in person." So I mulled that over. I terminated. Walked in--took--me a f--little bit. And I walked into his office and I stood there. This was like--I mean he had a been com--he's like, "I can't imagine life without you" in our appointment. I mean it's really--it was getting out--out of control. And I walked--I walked into his office and said, "You have"--I stood like proud and tall and I said, "You have done harm." You know, the Hippocratic oath. And, I said, "Dr. So-and-so knows and he knows you've been"--I said, "You know, you've been taking those medications and diverting them. For yourself." And he blanched. And I said, "And Dr. So-and-so is going to be speaking with you." And he blanched and he said—he went back in his chair and he said, "I'm sure he is." I said, "I never want to see you again or talk to
you. I am done and I'm outta here." And I walked out. And then they took over. And they
brought him before the ethical board and he admitted everything. I got interviewed by the
Department of Public Health. He admitted everything, he had his own attorney, and as long,
long, long, long--I ended up suing him, it was a nightmare scene, and I end up going down the
tubes myself. I turned into a raw--quote unquote raw mess. I couldn't find anybody to help me, I
didn't want anybody from around here. I got me out of Dodge, as it were, and—and got linked
with my doctor in out of town.

Interviewer (00:11:57): I'm glad you were able to speak out about what was happening.

P2 (00:12:00): I am too. I take great pride in that.

Interviewer (00:12:02): You should.

P2 (00:12:03): After--I've been abused many times, sexually. It's like, okay, I ain't gonna have
this jerk, um, no no, no, no, no. So, um.

Interviewer (00:12:14): Good for you.

P2 (00:12:15): First it's compassion, "Oh, I want him to get help." Oh, right. And then it took me
about--and I changed my mind real fast. [Inaudible, 12:22:21] I sued him and it got settled out of
court. It was a nightmare scene. Had to go, like, multiple times to be interviewed by the forensic
psychiatrist and it was god-awful, but I survived. But, that's that story. Talk about abuse by the
system, there we go.

Interviewer (00:12:40): Yeah. Yeah.

P2 (00:12:42): It was about as bad as you can get.

Interviewer (00:12:44): Well, I'm--I'm very glad you're working with someone who you like
now and who feels respectful.

P2 (00:12:48): Yes. Yes. Yes. I ended up in intensive outpatient. I mean, I couldn't even barely
drive back and forth I was so--I'd have to stop the car and get off the highway. I was so raw. I--I
keep saying that word, but I was.

Interviewer (00:13:04): Well, it's clearly an important one to you.

P2 (00:13:06): Yeah, but they wouldn't let me talk about it. They didn't want to upset other
patients. [Pause] So, that was that.

Interviewer (00:13:17): Um, so--I mean--you've already--you've already, sort of, talked about
some of the difference, but um, so you've--you've been using mental health care for some time,
now.

P2 (00:13:27): Since I was 14.
Interviewer (00:13:30): 14. And so this difference is a big one, but so what are, um, s--how does the care you're getting now feel different from care you've gotten in the past?

P2 (00:13:41): Um, [pause] day and night. The kindness, the, um, letting me have my own input, um, you know f--I'm still on a little bit of medication. But I discuss it with, uh, the--the doctor and she--psychiatrist and she says, "Well, what do you think?" She--you know--we talk--she let's me give input.

Interviewer (00:14:11): How would that conversation have gone years ago?

P2 (00:14:17): I was a frikking over-medicated zombie. I was obese. Uh, I couldn't talk 'cus my mouth was--when I started volunteering here, I was a zombie, my--practically. My mouth was, you know, dry, dry, dry. I could barely speak. Um. I had no clothes, you know. I had the history behind me and [pause] there was a time period where I didn't even talk. I mean, I might of--I said a little bit, but I just completely [pause] was into myself. But going back to when I was younger, um, I had my first experience was with a p--woman--psychiatrist, my mother finally picked up--it was early, I mean this was early history--and she picked up that something was wrong and linked me with a psychiatrist. And she was really my only friend. [Inaudible, 00:15:26] and then my fam--we got uprooted from one--from the state we lived in and we went back to the city where I was born and then my father had mental health issues too, hospitalized, hospitalized, hospitalized, ended up in the state hospital.

Interviewer (00:15:47): Wow.

P2 (00:15:48): And it was a nightmare. And my family fell apart. We left in the middle of the night, my mother, sister, and I. Left my house, my dog, everything I owned. Came back to here. No place to live, we stayed with my aunt and uncle. And, uh, um, I went to sch--senior year I did pretty darn well. And, uh, I got involved as an activist in the civil rights movement. This is right before, uh, 1960--64, so it was right before the civil rights act got passed. And I mean I was really an activist. But, uh, I also subjected myself--I was like, promiscuous. Very, very promiscuous. And I ended up getting raped. But I blamed myself and wouldn't tell anybody. "It's my fault," 'cus I let my so-called "boyfriend," who fathered a child--my child, my daughter that I had. And, first of all, the father was married and I had no clue, no clue. And he--he abused me, frankly. Yeah. Forced oral sex, all kinds of stuff. And then, one night--I--we had an apartment with a friend--one night, his, um, nephew came. He said he wanted a place to stay. My neph--part--my roommate was away. I said sure, I liked him, wake up in the middle of the night, he's on top of me. So, you know, it's blame, blame, blame. And then it was just--I got raped by this--my first boyfriend, when I was 14. And, I mean, he's my boyfriend, right? Raped. So--and multiple things related to that. And I've had a history of several rapes. Nothing in the family, but rapes, rapes, and more rapes. Molestations.

Interviewer (00:17:51): And so when was the first time that you, uh, went into trea--was when you were 14 and then were you in treatment again when you moved back here?

P2 (00:18:00): Uh, not at that time. I did--was doing pretty darn well. And then I got w--as I
said, then I had [pause] my daughter, I got pregnant. And so I went to all these places up in--first here and then out of state, and then ultimately a home for unwed mothers. And, um, I realized they're not going to let me keep my baby. They're not going to let me, I know it. Nobody was offering supports. So I threatened suicide. I was, you know, I wasn't going to give her up. I didn't know it was a she, I wasn't going to give my baby up. No way. But I started getting, um, I don't know if I just made it up or if was acc--true but they came and got me of course and they brought me home, my mother, to g--you know they're going to st--they, um, committed me. 'Cus of the threat.

**Interviewer (00:19:04):** While you were pregnant.

**P2 (00:19:06):** Yeah, I was pregnant. They committed me. So, here I was in the ancient--it was a city hospital. It was--this is in the 60s. So it's like this long, dark hallway—we're—I'm on a psych unit, I'm pregnant. I'm nine--eight and a half--eight months pregnant. And here I am, knowing I'm going to lose my ch--that's all I'm doing, I'm cry--I'm freaking out, because I'm going to lose my baby. So they--they put me in--uh--I wasn't really going to commit suicide. I just said it 'cus I just want my baby, okay. So, um, they put me in this hellhole. I was hyster--all I did was cry. Cry, cry, cry, cry, cry, cry. There were nuns there, in--sitting on the edges of their bed in there--I mean that were patients. And there—it was just god-awful.

**Interviewer (00:20:10):** And how did the people who worked there, how did they treat you, how did they interact with you?

**P2 (00:20:14):** All--nothing. All I did was sit in my room and then, uh, I mean suppose they--you know--I got food stuff and stuff, I don't remember that part. I just remember the horror of it. And I did remember seeing, finally, a psychiatrist and, you know, all I can say is I got hysterical with him and sobbed hyster--that's all I remember. Sobbing, sobbing, sobbing. So I said, the hell with this, I am not staying here. So, um, I got, uh, a--a pad, Kotex or something, whatever they called them then. [Laughs] Now. Anyway, and I put a little nick in my arm, somehow, with something, and I put the blood on the pad. I was savvy; I dunno how I even thought of that.

**Interviewer (00:21:02):** Yeah, that was smart! [Laughs]

**P2 (00:21:03):** Like, so, I thought--and so--you know what they did? They took me out. They put me on the--on a regular unit, because they thought I was bleeding. So then they sent me--I was--obviously I was okay [laughs]--and they sent me--they found som--a little home, a house, it was like a foster home kinda thing. They put me in that until I gave birth. And I had to surrender my little girl. I took care of her in the hospital, I held her for--they kept you like four or five days then. I lost her. But I found her, but that's a whole other story. But so I have to say that was god-awful.

**Interviewer (00:21:42):** It sounds like it.

**P2 (00:21:44):** And then, I just couldn't function. And so I ended up going--just staying home, sitting on the couch. I f--finally got to the point that I wanted to find--try to work. I went to work. Oh I got--I had worked for a dentist too, I forgot that part, right out of high school. He wanted to
hire me. I was ready to go home from work one day and he comes out with semen on his pants from the lab, and he goes, uh, "Here, this smells wonderful, wanna try?" He smothered me with chloroform to--to be sexual with me. He was a married man. I mean, this sounds outrageous. This is not hallucinations, this is fact.

**Interviewer** (00:22:36): No, no. I believe you.

**P2** (00:22:37): Fact. And there's a picture on the wall, right in the waiting room of his wife and his children while he's doing this. And I kept saying, "I'm dying, I'm dying, I'm dy"--I felt like I was dying! Maybe I was, I dunno. He held this rag--to this day I can't stand that smell. It freaks me right out.

**Interviewer** (00:23:00): I'm sure. That makes sense that it would.

**P2** (00:23:04): So, anyway. That's that lovely story.

**Interviewer** (00:23:09): So. So, you had these experiences of going in and out of these hospitals and sort of . . .

**P2** (00:23:15): Yeah, then I ended up--I couldn't do the job, went home and took a bottle of aspirin. Called my mother and said I'd overdosed with aspirin. So they put me in the state hospital. 19.

**Interviewer** (00:23:29): So, so through these experiences and then thinking about the care you receive now, how does the care feel different? Like, what is different about the people you're interacting with?

**P2** (00:23:42): It was so institutionalized, it was horrific, I mean--I mean, life in the state hospital? The beds were like this far apart. People were hallucinating and crying and sobbing all night. We wandered around the day room--just like, you know, what a--the stereotypical wandering around the day room. Um, people could smoke so there's a little thing on the wall so they light their cigarettes. There's no place to sit. There's one couch that every--or two that everybody's vying for. Um, I'll just say there was one person that--perhaps two, that were kind. Everybody else was just like horrible. It was just--a--and I got shock treatments with no freaking anesthesia.

**Interviewer** (00:24:32): And--and then after you went out of that hospital, what was the next treatment that you received?

**P2** (00:24:38): I think it was, um, yeah, I think it was locally. Oh no, they--I tri--I tried to work. I got--I don't know, I can't keep track of sequential--but, anyway, I--I got--I was in and out of, um, a city hospital. It was a nice unit, um, I'll just say. It was certainly a bet--way better, but, um, I ended up getting married and guess what? I turned around. Everything was great. And, uh, I was happy and I still didn't have my daughter, but I had my son. I had my first child. And my second child. But, my husband turned out to be a severe abuser of alcohol. And I had no clue. On our honeymoon, the second night, he got flat out drunk with scotch. And I cried myself to sleep. So,
you know, I'll say syst--a--system was starting to improve.

**Interviewer** (00:25:50): When do you--is there a, sort of, time that you feel like you saw the improvement begin?

**P2** (00:25:57): Ah, it varied. It varied.
Participant 3: Dinah

**Interviewer** (00:00:08): All right. So--um--so just to begin with, what kind of mental health care do receive these days?

**P3** (00:00:15): Um, I see a--a--I--I guess it's--um--I see a psychiatrist. I'm not in therapy that I go to once a week, right now. Um, only because the therapist that I was seeing--I w--I wasn't--I would say I wasn't even seeing a therapist once a week, I was seeing her more like once every two weeks or three weeks, um, just to, um, work on some areas that I felt needed addressing, um, like, um, weight issues and also--um--just some unresolved issues. So I stopped seeing her because she left the agency and went to work somewhere else and I haven't yet pursued it. And--and--and it's something that I may pursue again, but I spent a long time in therapy already. So I see a psychiatrist for medication management.

**Interviewer** (00:01:17): Were they both at the same, um, site?

**P3** (00:01:21): They're both at the same site, yeah. It's a local, um--well it was part of my catchment area originally, so it's a local mental health or behavioral health care sys--service, um, that, um, reaches a lot of regions. So, it's a--it's a--I don't even know if I would call them LMHA necessarily, which is a local mental health authority, but they--they do reach--they are that far reaching and they're funded in part by the Department of Mental Health and Addiction Services, so it's one of those facilities. Probably it is considered a LMHA unless you're . . .

**Interviewer** (00:02:07): But the only service you're receiving through them right now is the psychiatrist.

**P3** (00:02:10): Psychiatry. Yup, yup.

**Interviewer** (00:02:11): And h--sh--should you decide that you wanted more services, how would you go about finding those?

**P3** (00:02:15): Well, I would probably look for a therapist, um--at this point in my life I probably would look for a therapist outside of the agency. Um, mainly because, um, I might be looking for a job within the agency. So--so, I don't know if I'll do that but--so, I have the option of finding a therapist within the agency. I'm not sure I need a therapist at this point. Um, I know that there are times in my life when I--I do wish I had someone to talk to like that. But really, I was under--probably under utilizing, um, the, um, outpatient therapy program--adult outpatient therapy. So--so, I--at this point I don't have one. I use my friends if I want to talk.

**Interviewer** (00:03:09): [Laughs] It was--that’s my next question. So, when those times come up . . .

**P3** (00:03:11): I don't mean use but I mean consult friends if I need to talk to--about something.

**Interviewer** (00:03:17): So your social supports are able to feel some of those gaps?
P3 (00:03:18): My social--yeah, exactly. Yeah.

Interviewer (00:03:20): Okay, and, um, wh--how l--how long has it been now since you were seeing that therapist who left?

P3 (00:03:26): Oh, god. She just left, like, I--I wanna say within the past--I always lose track of time, but probably, um, it's December, so she probably left October or November.

Interviewer (00:03:39): Okay, so not that long.

P3 (00:03:41): It was a shock to me that she was leaving, because I did, um--it was--it was a transition for me that she was leaving and I didn't ha--we didn't have--I would say not just me, but we together as a working team, collaborative, um, didn't have closure because I missed an appointment that would've been the last appointment for her to see me and, um, so we had--we didn't have that closure and I haven't pursued where she went--what agency and she wasn't at liberty to tell me where so was going. So, yeah.

Interviewer (00:04:15): That's difficult.

P3 (00:04:17): Yeah, it was def--[laughs] it was. It was difficult. Yup.

Interviewer (00:04:22): So, how long had you been seeing her before--before she left the agency?

P3 (00:04:28): Um, she was one of--a newer therapist, like I--I've had, um, probably three--three therapists in that agency and she was the third one. And we started maybe like two years--maybe I saw her for two years. And then prior to that I saw another one for, probably, sssss--a long time.

Interviewer (00:04:55): Those are substantial relationships.

P3 (00:04:56): Sub--yeah, yeah, yeah. Probably--the other one I saw for a long time and--um--and probably the longest time and then I, um, started with, um, a therapist in the mobile crisis unit. So she would come out to--excuse me--she would come out to my house and we would meet outside in the community and--and things like that. At Dunkin Donuts or wherever. And then, um, when I [sigh], um, recovered enough to--to not be in the mobile crisis unit she transferred me to adult outpatient therapy and then I saw her for a long time. I've been in therapy for, like, 20 years whatnot, all at this agency, so.

Interviewer (00:05:48): So, there was sort of a--a process where you started in maybe a more in-intensive therapy with her and then switched to--and then to the new therapist.

P3 (00:05:58): Mhm. Yeah, yeah, yeah, yeah.

Interviewer (00:05:59): Um, so, uh, w--wh--and were--so you--with the p--last therapist you
had, you said that, uh, s--some of it was, um, sort of practical conversations.

P3 (00:06:11): Yeah. I went--I went to see her mainly about--well, I started out--it started out that I called back--well, after, um, I'm not sure why I left my second therapist, e--or maybe she closed my case, but I was seeing the--the woman I was seeing in adult outpatient, I think she changed her hours or--d--there was some reason, I can't remember, it could be a combination of--just--we weren't working well together, um, or she too changed the hours or--or I wasn't going regularly or something, not engaged with her, not connecting. She called me psychotic once and I was like [chuckles] okay then. Um, but, um, so--so, but we had seen each other for a long time, it just--it w--I--we weren't connecting. So, I stopped going to therapy for a long time and then I, um, started seeing, um, the third therapist and, um, it was originally to talk about weight issues and, you know, why I keep doing the same thing I k--keep doing, like doing things that are bad for me, um, in terms of, um, diet, nutrition, exercise, that kind of stuff. I just wanted to--to t--talk about the practical stuff that were impacting my self-esteem. So--so, we--originally it was that and then we were able to delve into some other issues. You know, I'm--I'm in a care giving role in terms of taking care of a elderly parent, you know, um--um--a lesbian woman involved in a biracial relationship, so we--we were dealing with things--lotta--definitely a lot of threads. And so--so we were talking about those kinds of issues. And we were able to connect on a much deeper level. Also, um, I'm someone who w--was going through, um--l--l completed a masters program in social work, um, which--which is clinical social work and I haven't been able to find a job as a clinical social worker. So it was issues that we were talking about. So and wondering the difference between me and, you know--even though I work full time at a--a human rights agency and we work with peers who are in recovery from substance abuse and mental health, so I was doing that kind of work and not--not really focused on my social work career even though I prepared to have a career in social work. Even as a--as a displaced worker. So--so that's the kind of stuff we were doing in therapy, so when she told me she's leaving and she's going to another agency--and she's someone who has some things that, you know, I admire and it--we made a connection that was much deeper, I would say the first therapist I had and the thir--in the mobile crisis unit and the third therapist I had there at that agency were able to connect around our profession. And--and--and--and--and so, um, you know I just felt more of a connection to, um, my first therapist who--first in the mobile crisis and, um, my third therapist. But, she left, so.

Interviewer (00:09:44): Would you say that there were differences in how they sort of approached you as a person or related to you as a person?

P3 (00:09:50): Oh, absolutely. Absolutely. There's a difference in approach in terms of their--um--the way they worked with clients and the way they transferred the knowledge that they had and listened.

Interviewer (00:10:05): Can you tell me what some of those differences were?

P3 (00:10:07): I think--I think--well, the first therapist was just a cool person. She was in the mobile crisis unit, she was just cool. And, um, to be honest with you, I'm aware of what her sexual orientation was as well and we shared the same sexual orientation, although she was involved with a partner, um, and, um, they--after we stopped working together as client and therapist I--I, um, also learned o--before that--prior to that, I learned that her and her partner
were married and--um--and they were having a baby together, so we were connecting around, um, that. It--th--that never entered into our work together, but it--it helped to--for her to have some understanding of who I am as--as a woman and--and for me to know that she actually gets it, you know? [Laughs] So, i--w--we talked about s--and--and she was instrumental in supporting me when I first started at the agency I currently work for full time. I started as a volunteer and I--but--but she knew me when I started at that agency as a student, um, in, um, their advocacy education program. So--so, before I even began working as a volunteer, I was a student enrolled in their advocacy education course and it was my introduction into the behavioral healthcare community in this state. ‘Cus I didn't know a behavioral healthcare community existed. Um, it was [sigh] probably five years into my diagnosis, my formal diagnosis, as--as somebody with a--a severe mental illness. So--so, she was really supportive of me. She attended my graduation from coursework and, you know, she came as a friend. Um, so, there was this--her--her whole professional style in interacting with clients were different.

**Interviewer (00:12:21):** It felt more equal, would you say?

**P3 (00:12:23):** Um, mm mm. [Laughs] It was clear that it wasn't--wasn't equal, I mean it did feel more equal it j--I just felt--it felt more human and it felt more like she just got me as a person. It- -I never felt like she was a friend, per say, but I didn't feel like she was someone who--because her role was to be with the patient in the community, so she came to the community. She would come to my house, she--she understood, uh, me and it was--she was just someone who was easy to talk to. She was just--it was different. I don't--I don't--I don't know what to say, I hope I'm not getting her in trouble or anything like that as far as the way she worked, but . . . she just kept it real. You know how you just have somebody that keeps it real with you and--and just [sigh], I dunno, she was just a cool therapist.

**Interviewer (00:13:26):** Well, I appreciate what you say; her, um--her--you know, being treated as a human. I think that that's a valuable experience.

**P3 (00:13:31):** Yeah, just--I--I mean, she saw me, probably, through and worked through some of the--the darkest days. Like, early in recovery. I mean, I wasn't--I wouldn't even consider myself in recovery at the time she was seeing me. And--and my self esteem and a--all of that, um, my--I--I was paranoid, I--I had a very low self-esteem, um, just because I was coping with a mental health diagnosis in the first place and she ss--she ss--she lived that through with me and saw me progress to the point where she said, "I cannot keep you as a client anymore. You have to, you know, move on from here. You're not in crisis at this point." And so that's how--but they stay with you and they're with you until you reach that point, until you are able to use your community supports and family and friends and--and stuff. But prior to that, I wasn't able to. Yeah, yeah. So--so, that's the different with connecting with someone who was like that. And also, I have to say, that she wore, um, I mean, her whole style and appearance was just different. Like--like a friend of mine, like the friends I have, you know, who dress a certain way and their way of being in the world is different. And so--and there are some people who--who don't--who, like me, like, have a standoffish attitude toward people. But, no, um, I--I couldn't do a--just the way she carried herself made it--made it comfortable. Made me feel comfortable. Yeah.

**Interviewer (00:15:23):** Okay. Um, so [clears throat], in general, the care you're receiving now--

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I know you've--you've been receiving mental health care on and off for--for quite some time, in
general, how does the care you're receiving now and maybe with this most recent therapist who
you're no longer seeing, how does that compare to experiences you've had in the past?

P3 (00:15:43): Well, I would say that, um, certainly h--if the past is the way I just described it,
that's--th--that was, um, probably--when was that? That was 2004, 2005, when--when I saw the
first therapist. But, um, [pause] so, prior to that is a--is a time when the--the mental health care
system left a lot to be desired. Individuals in the mental health care [pause] were kinder. Um, so
I--so I've had--if it weren't for an occupational therapist and--and I've--I've received--I have to
say--I've received mental health care in two states. And so, um, so from the ti--not--let's say 1999
to 2004, I was living in another state and--and I received poor treatment in a hospital there. I
was, um, restrained, um, for not being harmful, not being violent, I think by and large because of
the way I looked, um, and, um, placed in four point restraints because I, um, patted a--a patient
on the head and you weren't supposed to go into patient rooms, but I didn't know what I was
doing. But, I know I wasn't violent when I was abused like that. So, I received traumatic
treatment at that hospital and, um, and was forced to take medication which I later learned you
cannot force someone, um, to take medication unless you deem them to be a danger to
themselves or--or other people and I wasn't a danger. Um, so [pause] I was really traumatized by
the mental health care system, um, and--and multiple people, um, placed me on a gurney in four
point restraints and, um, I was naked. So, um, so there--there's some--I feel some kind of way
about that kind of treatment and, um, how I probably would not have been let out of that facility
unless I agreed to, um, take medication.

Interviewer (00:18:33): And that was the case?

P3 (00:18:35): And that was the case. Because, prior to that, I refused to take medication and so
the team, uh, the interdisciplinary team would come and, um, try to talk to me about taking it.
"Are you gonna take the medication? Are you gonna take"--"No, I'm not gonna take the
medication. Why do I need medication?" That kind of conversation. And I thought, um, at the
time, that I was being reasonable by refusing to take medication. There was no good reason for
me to take medication. But I quickly learned in that facility that--that--that went on for about a
week there, I was there for two weeks, it went on for about a week, until it dawned on me, um--I--
th--I was given Haldol when I was restrained and, um, the next day I actually did feel better,
num, calmer, um, and--and, um, one of my friends came to visit me and I said, "What," you know,
"what happened?" Or "Why am I feeling so much calmer?" Or this that and the other thing. And
he said that, um, he said, "You know, you had--you were medicated." And I said, "Oh, is that the
impact of medication?" And he said, "Yes." I said, "Maybe I should take it to get out." You
know, they're not gonna let me out--it wasn't, like, you know, the stuff I learned at A.U. about
patients rights being posted and, um--um, you know, having to know where, um, wh--that you
have the right to refuse and I thought I had been committed to this hospital and later realized that
I had signed paperwork so it was voluntary the whole time, but, um, I think they were gonna
commit me, um, yeah. So, it was just a really bad, um, scene. I'm trying to talk about it really
detached [chuckles] but I'm getting angry at this point, but, so, it's really kinda pathetic.

Interviewer (00:20:41): If you need to feel anger about that, that's also okay. [Laughs]
P3 (00:20:44): Yeah, [laughs] yeah. You know, i--what happened to me and what I later learned when I moved back to this state about the rights--patients bill of rights is, you know, something that was obliterated--my rights were obliterated, no one told me, I didn't know--I really was shocked, um, that, um, that I was even admitted to the hospital in the first place. I agreed, um, to go and be evaluated, um, because of a--a situation that occurred between me and a girlfriend and, um--so going through that experience I learned that there's a certain way a patient has to talk in order to be heard and in order to have what we desire to have. And so what I did was agree to take the medicine so that they would let me out of that facility at some point and so--so the next week I started a medication regimen and was, um, discharged on my birthday, um, and that was a week later. So, it was in February of 1999, um, and, um, they let me out. And then I went and I saw a doctor and learned quickly, you know, when you go through the many mental status exams, um, that there are certain ways you have to answer those questions and there's certain ways you have to look in order to get over--in order to--for the--the providers to view you a certain way.

Interviewer (00:22:35): Sort of what the expectation is for getting . . .

P3 (00:22:37): Yeah for--yeah and--and--and all the talk was about being med compliant, being treatment compliant and it really is pathetic, but that's what I went through in order to--to have freedom and the freedom came with a price also. So, I also had family members that weren't advised of my rights or--or their rights as family members. I, you know, I had people who would just say, "Take your medicine, take your medicine, take your medicine" in my family, so the boundaries between them and the issues in--in terms of the relationship healing, is taking some time because I still never forget, although I forgave them for their role because they had lack of information. But, I went through something and--and I hope to never go through it again and it--it is probably what propels me forward to--to not have those times return for anybody I know. And, um, it is what, um, led me to want to be a part of an organization here so that we end restraint and seclusion, because of my experiences in restraints. And I was restrained after; I was actually restrained in this state, in a hospital here, as well during that time period between 1999 and 2004 probably.

Interviewer (00:24:09): And was that experience--I'm not quite sure how to--how to f--form the question I have.

P3 (00:24:18): I'm sorry.

Interviewer (00:24:18): No, no. Uh, was that experience, um, did it feel different than the experience that had happened the first time you were restrained or was a--d--s--did it feel similar or the same?

P3 (00:24:28): It felt like the more things change, the more they stay the same. And it felt, probably, o--I--they both were pretty traumatizing. Um, when I was a child, I was molested and no one listened to me and I didn't tell about the experience. So, i--it felt like my body wasn't my own and no one was available to hear me or didn't care how I felt. Um, it felt punitive, not healthcare. And so, the experience with the four point restraints was unreal, I--I mean I—'cus prior to that I really thought of myself as, not like above the law or--or--or better than people, but
just, like, why would you do that to a human being? I--I just--and--and so I just felt like I was a human being and this kind of treatment can't be real. So, that's how it felt in that experience an--and here when I was restrained at, um--um [sighs]--um, a hospital--um, I was taken by police from my parents' house and, um, brought to an emergency facility and, um, restrained for I--God only knows why that happened to me, I still don't understand it, um, but it was, um--the difference between the experiences is that it was two point restraint versus four, so.

**Interviewer** (00:26:16): So it's just the upper body?

**P3** (00:26:17): No, it's the, um, one side of your body. And--and--i--the only thing I can tell you is that the experience of being in restraints--but, first of all, um, it was again to be compliant to medication that I didn't want to take ever because I was someone who had weaned myself off--I just don't have the same world view as th--a Western world view, that "take a pill and you can be fixed," and so it's never been. The only reason I continued to take medication then and took it then and continue to take it is because I have a family and s--three family members in particular, who believe in Western medication, in pills, and believe--an--and didn't believe that I had a right to choose what kind of treatment I--um--I accept, you know. They didn't believe that the--the decision to take meds or not take meds is between me and my service providers. Evidently, 'cus i--that would be the only reason that they would encourage me to do that. I happen to believe that it's between me and my service providers. So--[sigh] so, that's pathetic in and of itself, to me, still and [laughs]--and also the way the behavioral health care system at the hospital was--was pathetic, because they restrained me, um, and the only thing I could tell you is thank god I had practice, um, in my undergraduate, um, life [pause] like transcendental meditation or yoga, because the only way to deal with four point or two point restraint is to go inward, to try to calm yourself because what happens is I was like confronted with "take your medication" and my blood pressure went through the roof and I'm in these restraints and you can't move and you can't scratch or whatever, um, anything. You--you--you can only free yourself within and so that's what I did in order to get through the experience until they removed them. And I'm not saying that I'm perfect, but I'm saying no human being deserves that.

**Interviewer** (00:28:49): No.

**P3** (00:28:50): It's just--no human being deserves that, so. So, um, that is far from recovery oriented, I think. [Laughs]

**Interviewer** (00:29:02): [Laughs] Yes, probably.

**P3** (00:29:03): Yes, so, I mean, the way we treat--treated people, yeah. So, that experience lives with me still, um, I try to talk about it in a detached way, um, until I meet other people who have gone through the experience and I say, "I know what it's like and I know how it makes you feel." And you don't feel like you have the power to do anything, not change the system, not do anything. So, [pause] yeah.

**Interviewer** (00:29:36): So, as--as much as you're able or willing now, can you tell me how it does make you feel?

Interviewer (00:29:47): And if that's--if that's too much, that's okay.

P3 (00:29:49): Well, I was--how it makes you feel?

Interviewer (00:29:51): Yeah.

P3 (00:29:52): Um, [pause] certainly dehumanized. Um, [pause] hm. [Pause] I just, you know, I think it strengthens my resolve to never be a person that makes other people feel that way. So, I mean, that's--I try to look at the b--bright side of what going through an experience like that [pause] causes. But--I've written papers about it too--um, that, um--it traumatizes you. And it traumatizes you in a way that--like I said, the only [pause]--like, I have to relate to it, excuse me, from a spiritual perspective and I think, um, [pause] f--I'm angry that that happened to me. I continue to be angry that that happened to me. And--but I know that I'm not alone, so I'm angry that it's happened to anybody. And, because I--it's just not [pause]--I like to think I'm a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. A--I think none of us--there--there's not a single solitary soul that I feel deserves to be placed in four-point restraint. It is the most dehumanizing thing and if we call behavioral health care "care," then where is it [pause] when it comes to that type of treatment, isolation, restraints, whether they're two point, four point, wrapping people in chains or, you know, where--where is it? That is the--if you wanna make someone feel dehumanized like a dog or I mean I don--we don't even treat animals like that.

Interviewer (00:32:33): Not legally.

P3 (00:32:34): That's [laughs] y--we--the Humane Society exists to stop that kind of treatment but where is the human Humane Society? And when it comes to psych treatment--and we call it treatment, how do we call it treatment? So, the fact that that's our history sucks. I just--I don't have the words. I just--I d--I just [laughs].

Interviewer (00:33:00): That's all right, that's a good one for it.

P3 (00:33:03): Just, yeah. And--and we expect people to emerge from that unscathed. I think we do, right? Take your medicine. Um, so, whether it's chemical restraints or--or physical restraints, they're both equally, to me, treatment that sucks. There has to be a better way. And I think we haven't found it yet. We--I mean, one state hospital has increased restraints--restraint hours, people have died from them. Um, yeah. I'm angry still. I just--I'm trying to contain myself. My friend says, "You're so calm, you're so calm," I'm like, "inside"--I know, because--no, I know looking like me I have to say--I have to say, I dunno, because at the time my hair was in locks, you know, I might have--I looked bigger, I--I weighed more, um, I--I'm not saying there's a difference, but I'm saying there's a difference in how you're treated and I--I--I would say I was restrained by at least seven or eight people, most of them were men, and the way that--like I--I wanna know this: how do individual people allow themselves to treat other human beings like that, policy or no policy. I just--I just don't know.
Interviewer (00:34:42): It's an important question.

P3 (00:34:43): I just--I don't get it. And if it wasn't for the occupational therapist on that unit, I would really have lost faith in humanity.

Interviewer (00:34:54): But there was a, [clears throat] pardon, a person who you--who was reaching out to you at that time?

P3 (00:35:00): Yeah. Not during that particular time, but it was--it was the other patients in the unit and the occupational therapist that actually [pause] helped me with washing my clothes after I agreed to take their medication to get out. So, she actually treated me like I was a human being, regardless of her job, you know. It was like she went above and beyond to be kind. She was someone who [pause] [laughs]--maybe she didn't like the treatment, the way they treated patients on that unit herself, um. I--I--I can't think of a kind nurse, I can't--the doctor, she wanted me to take medicine and so that was her goal, for me to take medicine in order to get out and not say--I mean, she didn't say, "Okay, well, let's look at some alternative ways for you to heal," she didn't say that. For her, medication was the . . .

Interviewer (00:36:17): That was the answer.

P3 (00:36:18): The answer, yeah. And--and--and talk about cultural competency and respecting somebody's desires not to take a pill, not to take a chemical, and--and so--and even members of my family didn't get it, and so I knew [laughs] I would be stuck in that facility if I didn't adhere to their wishes.

Interviewer (00:36:43): Yeah. And so, between these two hospitalizations were you receiving treatment outside as well?

P3 (00:36:51): Mm mm. Prior to--prior to that I didn't have a--well, here--before I left, 'cus I have--this was--this hospitalization occurred maybe a week after I moved to a different state. So--a different city--and so--so prior to [sigh][pause]--prior to that, I was asked to take a leave of absence from work. I was working and I was asked to take a leave of absence, because I snapped at one of our students who asked me something personal and probably my boss was like, "You need to take care of yourself. You need to get some rest--see somebody." And--and so she--she was of the mindset that I did and I agreed with her, so I went and I finally said, um, 'cus I'm a voice hearer, so I finally said to somebody, "I hear voices." And, um--a psychiatrist this time, prior to that I had gone to a psychiatric nurse and, you know--so, I, um, I went and he immediately said, "Well, how long have you been hearing voices, what is the content," you know, the typical questions you get. And, um, I said--um, I answered his questions, he sent me away with a prescription for Risperdal. After a while, I went back to work, 'cus I could still keep my job and, um, shortly after that I decided to move, which was a mistake, obviously, in my life, you know, hindsight is 20-20, moving away from, um, this state was a mistake. So, I moved and, um, ended up in the hospital with that treatment. So--so, that was huge, but i--doesn't matter, it still happened here as well after I moved back [laughs], you know, that I was restrained again and--and when I say that I didn't do anything to warrant those restraints, I mean that. That is not som--I--I--I--who does anything to warrant that, I mean I understan--I wasn't like, escalated--
people wanted me—people restrained me in order to get me to take medication or because, like I said, I had gone into a patient's room in a--in--in--in a distressed moment, I walked into his room—I was having an experience where I felt like--this was pre, uh, reuniting with my son--I'm awful--also a birth mother--and, um, I was having a dream, I think, I had a l--it wasn't--it wasn't a nightmare, it was a dream, where I felt like my brother was talking to me and I went into the patient's room and I rubbed his head and I called him my brother's name and that was it, but evidently I didn't have on any clothes at the time and, um, had been going through something, but I wasn't a danger to the patient and I didn't do anything that was violent and that was why, um, I had--they asked me to go back to my room and I was like still probably in a malaise or something and, uh, didn't want them to tell me to go back to my room or something, but it didn't warrant eight people throwing me down on a gurney and restraining me for a night or whatever. Yeah, it was crazy. So--so--so that was my pre-recovery oriented [laughs] system and pre-knowing about my rights. That kind of thing could never happen to me again, I know they say never say never, but, um, yeah--make sure it doesn't happen to anybody else. So, yeah.

Interviewer (00:40:50): So, um, so if you're thinking about, um, the--the providers or professionals you've worked with in the--now or recently, compared to those you worked with in the past, what--what differences have you noticed between the two?

P3 (00:41:08): Um, I think providers now--the provider that I have--the psychiatrist that I have now listens more, um, I--I think, um, he's learned something from, not just me as his patient, but his other patients to listen more. It could be he's learned something from the Department, from his practice to--how to listen to his patients. How to--because he, um, confided in me this story--I tell this story when--when I'm doing speaking engagements too, because--not the story I just told you, I haven't shared that part of my history with anybody, so--so, um, except a few select people, so it's not public knowledge.

Interviewer (00:42:04): I appreciate your being willing to share it with me.

P3 (00:42:06): Yeah, I'm gonna share it with you because you're doing a dissertation [laughs] on what the system was like and that's how it was for me, um, but he--he, um, said that he has patients with, um, tardive dyskinesia so bad that he can't continue to prescribe anti-psychotic medications to them. And so he's working with me in reducing medication, the anti-psychotic, 'cus one--one of the things that happened is while I never desired to be on any psych meds in the first place and, um, I've taken a lot of them over the course of that time--from that time--from 1999 to the present and I've taken a lot of them, some of them I had adverse side effects too and e--everything, but it has to be not only, um, to satisfy my family and hate myself every time I take them, but also it was to--to get out of the facilities in the first place and then to satisfy my family, who, like I said, believed that you should take medicine if you have a mental illness and then it was my own doing, like I take full responsibility for continuing to take it even though I feel some kind of way about, um, taking it and its effectiveness. It has never stopped the voices that I hear and, um, I don't take anti-anxiety medication. I used to take that 'cus I experienced an--um--anxiety, um, social phobia, I couldn't be in public--in the public period. I couldn't go to grocery stores, I couldn't, um--um, do events. I--I--I was teaching prior to that in front of groups of people, that's my role now in the job, um, teaching, um, and being--I couldn't be in public places, I couldn't facilitate support groups where there were people talking because of the
voices and--and--my experience with voices, not because of the voices, but because of my experience with, um, the voices and how--they make me cringe sometimes and so feel out of sorts and feel--you know, I couldn't do it, so--now I do it, but--so--I have recovered--but I think, um, i--so he said he has tardive dyskinesia--he has patients with tardive dyskinesia so bad--and even though he checks me or whatever--he listens to me--it's a 20 minute appointment, but he listens to me and he knows that I facilitate a Hearing Voices group for people to talk about the experience of voice hearing and all of that kind of stuff. I'm involved with the Hearing Voices Network and we brought this to the State through, um, someone who worked for the Department of Mental Health and Addiction Services and, um, we have 14 groups now, we started with six and so there's, um, [pause] we have a voice and I have a voice today that I didn't feel I was being heard by service providers. I still think there's some service providers who don't hear me when I speak, who don't recognize that we do have choices, as people with a mental health condition we have choice--ultimately the choice should lie within us, it should be between me and my service provider, not other people who think they know what's best for me, but it should be between us. And so, I have an attitude about it, I know you could probably hear it and some anger [laughs], you know--anger about it, uh--so--so but I--I feel like my psychiatrist, at least, is getting it and he understands and he's--he's not certain what the outcome will be with me, but at least he's willing to work with me and say, "Okay."

**Interviewer** (00:46:26): Yeah. So, if you're comparing him to other psychiatrists you've worked with, he is m--he is more able to do those things than they were?

**P3** (00:46:36): [Deep breath] Yeah. The psychiatrist I had out of state, he's been the--p--probably the--I--I had another one in a partial hospital program that was different from him, but I've been with him since 2006, maybe 2005 or something--he's been my psychiatrist for all this time. And so he's seen my growth and development as a human being, as a professional, um, and I think that has probably made a difference for him. And also, his patients like over time--and c--you can't be in behavioral health here without knowing that recovery is possible, I don't think. Is it possible to--to--to not know that? It's--it's real for people and--and there's some alternatives that we need to be about integrative medicine, holistic healing, um, offering people choice. People want to be offered choices and not--people want to be a part of their treatment plans. So, I think we have a long way to go in terms of, um, helping people because I still think the difference--you asked me about some of the treatment providers and I know, um, we have a little time, but, um--that--um--I think the third therapist that I had still--and probably m--m--my lack of insistence that I be a part of the treatment plan, like they're still using the old treatment plan, like, just to get you to sign, so that they could get f--uh--funding. I think that still is an area that needs to be addressed. We have a document that, um--um--Yale--um--is responsible for the p--hiring staff that put it together, called Getting in the Driver's Seat of Your Treatment Plan. That still--that document is not being utilized everywhere and so it--it--it's still--uh--we have a long way to go in terms of helping [pause], I'm going to call them patients, but helping people get in the driver's seat of their treatment plan with agencies because I--even--even me, knowing and teaching it, I still go to a facility and at the most recent treatment plan I signed, I really just signed it. We didn't have a conversation--the first--about what are my goals, although she knows, I want to get a job as a social worker--that's not in there, so, you know, um, she knows.

**Interviewer** (00:49:22): So this is at that program where your--your therapist was?
P3 (00:49:24): Yeah, yeah.

**Interviewer** (00:49:25): So, um--so, I wanna make sure that I--I ph--phrase this correctly--so that, um, part of what you're seeing is that the change is there but that the--the client, the consumer has to be--um--has to--has to push for it, because otherwise it's st . . . yeah?

P3 (00:49:47): Yeah. I think--I think otherwise there's a risk that it will continue at the status quo. It will con--business as usual will continue, if we don't, as clients, insist that we're a part of it, that the conversation takes pl--like, it's almost like insisting that, "Are you gonna ask me?" And--and we can do it nicely, we don't have to be hostile like I am. We could [laughs]--we could do it like, "Are you gonna ask me" [laughs] "what my goals are in different areas of my life, do I have financial goals, do I ha--wanna own a house or get a different apartment, do I want to have, uh, social relationships that are rewarding?" You know, "Are--are you gonna ask me those questions?" And I think we have to insist, as clients, that the qu--give them the questions when they don't have it. But, I also think some training has to take place on the part of agencies' staff development. Like they should--they should know that that document exists, especially some of them coming out of, um, programs--therapist--social work programs, they should insist that, um, they should know about those documents and other documents. They should know about WRAP, they should know about--um--you know, because a lot of people in this state who are clients have a WRAP and if the--the clinicians don't know that there's such a thing--I mean, I don't know who doesn't know, but I'm sure there are some that don't know that it stands for Wellness Recovery Action--do you know what the WRAP is?

**Interviewer** (00:51:30): No, it's different in every city.

P3 (00:51:31): Oh, it stands for Wellness Recovery Action Plan and Mary Ellen Copeland--um--Mary Ellen Copeland developed it and SAMSA uses it--there's no such thing as SAMSA, but the Health and Human Services Department, uh, uses it, um. You know, it's called recovery planning or planning recovery, recovery action planning or something. It's been translated across, um, the globe and, um, people use that to help them manage their symptoms and to take action when they need to address certain areas. It is possible to use programs like a Wellness Recovery Action Plan and--as well as holistic healing and manage our symptoms without medication. I believe. This is just me. But if another person believes that they need a little medica--and I still take medication, but if an other person need--they need a little medication and they need those other things, then a therapist should support them in continuing to do that and that's the kind of education . . .

**Interviewer** (00:52:38): So were there--were there other people beyond the therapist you were working with or other experiences you had at that program where you felt like . . .

P3 (00:52:46): Well, I found myself in a position as a client of sharing information with my therapist that they don't know. And not only that, as a s--spouse of a woman who is in private practice, sharing information with her that she then shares it with her therapist that they don't know in private practice. I find myself in that role all the time and I--I was like, "Why don't they pay me to te" [laughs], you know?
Interviewer (00:53:14): Well, maybe they should.

P3 (00:53:15): Yeah, I know [laughs]. It--it's so funny. I j--I--I ju--so, but really the benefit is that my therapists treat me better as a result and--and I also learn from them, I don't--'cus I don't know everything, so I also learn from them. Like, that's why the third one, when she left, I experienced that loss greatly because, you know, sh--you know, I was learning a lot from her as well, so--so.

Interviewer (00:53:42): But that you do still see that there are these places, yeah . . .

P3 (00:53:44): But there's pockets that people need training, they need professional development. And that isn't all about they need advanced learning in--in those areas and--and sometimes it's unfortunate when the schools don't prepare them. Like, um, I went to this agency as an intern and the director of the agency said, "You know, the school that I went to is still using the same curriculum 20 years ago." And, you know, while I found it rigorous it--and it was kind of an insult to hear her say that [laughs], I was like, "Wait a minute," 'cus I learned a lot in that program, you know, and, um, the teachers weren't outdated at all. But I know that, but--but it's still the same thing about what they want professionals coming out of masters social work programs to know and be able to do. And that's not the only game in town in terms of where our clinicians are trained and what kind of schooling they have before they . . .

Interviewer (00:54:48): And do you think there--ho--um--what are the differences in how you were treated as a person in--in these--you know, over this time?

P3 (00:55:00): Um, I've been at the same agency in this state s--since 2004, so, um, [sniff] I think the biggest thing that, um, my--I--I think my therapists view me as capable and, um--um--competent and they didn't always. Like I said, like the one that I had prior to the third one--the second one, she called my psychotic. And she did--and--and I thought, "Why would you call someone that label?" You know. I mean, I can't remember the whole context to give you an idea, but I just think that's a travesty. Especially when you know that uh--I--I can't figure out what happen--I can't make excuses for her. I just think that I--I--I would be making an excuse for her, I can't--we were having a conversation and she was like, "Yeah, but you're psychotic." And, um--and--um, she was trying to talk to me about something, you know, maybe it was a conversation about medication, again. It's always been u--f--for them, it's always been about "Y--are you taking your meds" or, you know--even--that wasn't her role, her role was to do talk therapy. So, I think . . .

Interviewer (00:56:44): That conversation, it sounds, has eased a little bit, but is not gone. Is that true?

P3 (00:56:48): Yeah. It's--it's like using stigmatizing words--I can't think ever of a reason to be engaged with a client over a--a--to have a conversation with a client, ever, that I would call them a label that is in their file. I wouldn't. For what reason--can you? [Laughs]

Interviewer (00:57:15): I me--certainly not one that they didn't want to use themselves, you
know.

**P3 (00:57:17):** Right. I would refer t--to clients the way that--in fact, I--I was in a conversation with someone--even a conversation with one of my friend's parents and I said, "What is your first name?" And she said what her first name is. And I said, "How would you like me to c--call you--what would you like me to call you? By your first name, by a Christian reference--um--prefix, or your last name? And she said, "Whatever you feel comfortable with." Well, she's my friend's mother, so, you know, I don't know. I have to decide what I feel comfortable with. But I wanna demonstrate respect and so I think that the difference in the system is that, for some reason, there are some people still who don't believe they should respect clients. And that's a problem. I think. But that is disrespectful, I think, to call someone psychotic when that's not a word I use to refer to myself under any circumstance.

**Interviewer (00:58:22):** Yeah and I would agree with you.

**P3 (00:58:25):** So, I mean, more power to the people who do, but I just don't want to call myself any label.

**Interviewer (00:58:34):** And that--that should be your . . .

**P3 (00:58:37):** Other than my name [laughs].

**Interviewer (00:58:40):** [Laughs] That's a good one to use. So, um, h--how does--how does your work with these more recent providers, how does that make you--how does that work make you feel about yourself?

**P3 (00:58:54):** [Deep breath] I feel better about our relationship. I feel better going to him. Like, I know, he's--today's Friday, right? So, like, I missed our appointment--I meant to call him yesterday to say, "I need to come back sooner," but so--so, I know that he is con--extremely busy, because the agency doesn't have many psychiatrists. He also works in private practice. So with my, um, psychiatrist in particular, I feel much more comfortable waiting the amount of time that it takes, like sometimes he'll say two months, sometimes he'll say three months. Right now, we're, um, decreasing my medication, so--so I see him more regularly and I think that--um--that I feel much more listened to, much more heard, even though--within the time constraint. So. Yeah.

**Interviewer (00:59:55):** Yeah, yeah. And does th--does th--how does that interaction with those-that--that provider or your previous therapists, how does that make you feel then about, sort of, the world outside of those interactions?

**P3 (01:00:09):** I wish it were true for everyone. I don't--I don't think it's true for everyone. I think--I wish it were true. And I--um--I know that [pause] service providers are human too, right? They have good days, they have bad days. Perhaps I'm giving you an assessment of the second therapist I had on her bad day. You know, I don't know if it was a bad day for her. I do know that she was, of the three I had at that agency, she was the least willing to talk about or answer questions that I had about her personally. And while, I mean, I shared some stuff with her, even still, that I know probably was hard to hear, but she still disrespected me I think in that
instant, even if it was a bad day. She disrespected me and I carry that, 'cuz I've shared that story with other people and they're like, "What, she called you what?" I said, "I know!" I--I couldn't defend myself, 'cuz one of the things that I don't do is self-advocate very well. I teach it to other people [laughs], you know, it's one thing to teach it, it's another thing to practice it I think, but I--we--that's the kind of advocacy we teach, self systems and legislative. For years! I--you have to speak up for yourself, I know, but there's--there's something that prevents me from speaking up and it's probably because stuff like that hurt me deeply, like being called a name, hurts me so deep, like to my core, that I don't always have the words to combat it. And also, it's because I know it's either going to hurt me deeply to my core and I'm sensitive or I'll get angry about it and I don't want to explode, because the cost of me exploding is much greater [laughs], just because I'm a black woman, it's greater. It's greater for black men; it's greater for black women. And I know that people will say anything--a--it happened to me at the Department of Motor Vehicle. The woman was talking to me in a way that I felt you shouldn't talk to human beings like. And instead of saying anything--'cuz I said, there's a lot of people, a lot of witnesses, they won't witness her talking to me in a disrespectful way, they'll witness my response. And so my response was to walk out because I don't want to make a scene, because I will end up one of two places: jail, and I don't want to end up there, I never been there, or a psych ward, and you know--and--and so I--it can't happen. You know. The way I would get treated by law enforcement officers is much greater cost to me than--and I learned my lesson and that's the lesson, unfortunately--is the lesson I learned. That the thing you think won't happen to a human being will most definitely happen to me. And so--so, that's the stuff that makes you cry if you allow yourself.

**Interviewer (01:03:29):** It's a terrible lesson.

**Interviewer (01:03:43):** Absolutely. Those are terrible lessons to learn.

**P3 (01:03:46):** It is a terrible lesson to learn. But I learned it well.

**Interviewer (01:03:51):** Well, I'm--u--those are sort of all of my major questions. Is there anything else that you'd like to share with me? That you feel like I didn't ask about that's important to know or . . .

**P3 (01:04:01):** I can't think--I'm gonna have to apologize to you for--is, uh, talking so much and, um . . .

**Interviewer (01:04:06):** No, no. Of course. Don't apologize for that.

**P3 (01:04:09):** Not giving you a chance to catch a breath or . . .

**Interviewer (01:04:12):** No, it's--hey, I don't have to take notes, so it's fine. Don't worry about it. Um, and then just so I make sure I have some of the bare facts is--so how old are you now?

**P3 (01:04:23):** 51.

**Interviewer (01:04:24):** 51. And how old were you when you began receiving treatment?
Initially.

P3 (01:04:32): Mm. Oh God, 17. Maybe? But that was--we didn't talk about that. So, um, 17, um, because, um, I had some depression and so--but the mo--the--the part we talked about, I was probably, um, it was probably 1998. So, I was born in '64. So, 35.

Interviewer (01:04:59): Was there a significant gap in between when you were 17 and--and 35--significant gap in treatment?

P3 (01:05:08): I was in--I was in informal trea--I went to--I went to treatment la--I told you I was a birth mother?

Interviewer (01:05:14): Yeah.

P3 (01:05:15): So, I had my son at 18 in 1982. I went and saw a social worker then and that's what prompted me to--my interest in social work, um--um, I think is not having an adoption handled the way mine was handled. But--um--so, I wasn't in treatment until 1998 when I was asked to take a leave of absence from--from work.

Interviewer (01:05:43): Okay. Okay. And how many different treatment programs have you been involved in over the years?

P3 (01:05:51): [Deep breath] Y--y--are--d--d--do you consider private care--are you considering private care? Probably it was--probably it was a little bit sooner than 1998, 'cus I went to a--um--uh--psychiatric nurse for a brief stint. Like, I always felt like I needed therapy--like, I believe in therapy. So that's the first thing. I believe in talking to someone and trying to figure out what's going on with you. Like, other people were saying to me, "You need to talk to someone," [laughs] "you need to talk to someone, 'cus you're a sick individual." So, I finally agreed and went to someone and, um, you know I had several diagnoses. She diagnosed me with ADHD and--and then in 1998 I went to a psychiatrist because I couldn't deal with the voices. I would go to my window and look outside and hear things and not see anybody. So, I was surprised when [laughs]--when, you know, it was happening in a classroom--being in a class and looking outside and--spent a lot of time at work, um, teaching--I was teaching adults then, um. And, you know, finally I just couldn't deny that I was having an experience that probably other people didn't. But, for a long time I believed--which is why I didn't do anything about it--I believed that everybody could hear what I was hearing. So--so, I'm still not convinced [laughs] about that [laughs] to be honest with you, but I do know that they say one in 10--you know, what I've learned from the Hearing Voices Movement is they say one in 10 people hear voices and other people--and--and the problem is not hearing the voices, the problem is how you cope with what--what you experience. So, I think, in part my experience is spiritual and in part it is just, um, my experience. And that other people really don't--but, it surprises me, I have to say that, um . . .

Interviewer (01:08:01): Well, it's hard to imagine, when something has been there for you--it's hard to imagine it not being there, right? It's hard to imagine that.

P3 (01:08:04): I know. Yeah, yeah, when people say, "No, I don't"--you know, I was like, "You
gotta be kidding." But, [laughs] how can you not? Because they're always with me 24/7 and so, like I said, the--the medication only helped, um, calm me, i--it didn't ever have--I think it focuses me, that's the impact that--but, I take a medication that other people wouldn't be caught dead taking. And so, every time--I used to take the maximum dose of it, I don't take the maximum dose anymore and sometimes I wonder if I should and sometimes I quite frankly wonder if I'm addicted to it and that's the reason I won't stop it completely. 'Cus why take something if you are under the opinion that you don't believe it works at all? . . It never worked, I mean . . .

**Interviewer** (01:08:58): It's also very difficult to--to go against something that your family and community want. It's very difficult to stop when that's something, um, yeah.

**P3** (01:09:05): Yeah. Yeah. Yeah. It is. It is. My family had the biggest influence of--on me other than--and--and they would have conversations with the doctor, so, um, the--really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak, but--and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years and, you know, I've done other things I don't like. Like I said, I'm not perfect, but, yeah.

**Interviewer** (01:09:45): So, overa--you saw the--the social worker when you were a young adult, and then a psychiatrist, and then you were in the hospital twice, right?

**P3** (01:09:56): No, four times.

**Interviewer** (01:09:57): Four times. And then you saw three different therapists. And then the psychiatrist you're seeing now, right?

**P3** (01:10:05): Yes.

**Interviewer** (01:10:06): Okay. All right. Um . . .

**P3** (01:10:07): Um, I will say I was hospitalized four times, um, from the period of 1999 to 2004. One of the hospitals actually had an expressive arts therapy program, so--but I was also isolated from the unit and I probably left there too soon, um, because when I realized I could sign myself out I did and then I tried to go back [laughs] and they wouldn't let me. So--so--so--but that one had art, music, um, it was probably more humane. I was never restrained, but I did get--I couldn't have shoestrings, I couldn't shave, I couldn't do anything like that. And so, in some respects, um, that kind of treatment for someone who, um, I'll just be honest about it: that kind of treatment for someone who has a higher level of testosterone, 'cus I do, um, and grow a beard, um, because I started shaving, um, the hair on my face instead of waxing it, to not be able to use anything to shave--so, I really had a full grown beard and the impact that that had on my self esteem in the hospital can't be underestimated. Because other peop--I usually don't allow the public to see me like that and so other patients, nurses, doctors, everybody saw me with a full grown beard. And because I wasn't allowed t--to take care of it without, um, people seeing me. So.
Participant 4: Dolores

**Interviewer** (00:00:03): Alright, so [clears throat] I have, um, sort of a general outline of questions that we can use as we go along, but I--I would also be more than happy for us to move around a little bit within that. So--um--so, you needn’t feel too constrained by it. But just to start us off, what kind of mental health care do you receive these days?

**P4** (00:00:25): Well I have a therapist and--who's a psychologist or a social worker--and then I have a psychiatrist who I only see every couple of months or so for medication basically. And I was in a group therapy also, um, but right now, um--I lost my mother in July, so . . .

**Interviewer** (00:00:47): I'm so sorry.

**P4** (00:00:48): Yeah, thank you. So, I'm in a grief support, um, group so I--I'm not going to the, uh, other group because it meets about the same time.

**Interviewer** (00:00:57): Ah. And so how long have you been working with that therapist and that psychiatrist for?

**P4** (00:01:05): Hm. Well, since it's a clinic, um, I've had changes of therapists and things like that . . .

**Interviewer** (00:01:15): Mm. Within that clinic.

**P4** (00:01:16): But, um, I'd say, at least maybe two, three years.

**Interviewer** (00:01:21): Okay, so quite some time.

**P4** (00:01:22): Yeah.

**Interviewer** (00:01:23): Okay. And, um, h--how long have you been at that clinic?

**P4** (00:01:28): Um, let's see, since about 2006, so almost 10 years I guess, yeah.

**Interviewer** (00:01:39): So, that's a place you have a long relationship with.

**P4** (00:01:41): Yeah.

**Interviewer** (00:01:43): Okay. And, um, ar--so is the--the group therapy that you attend, is that at the same clinic?

**P4** (00:01:50): No, this is through a community center.

**Interviewer** (00:01:54): Oh, okay. Okay. S--um, and the--the grief counseling is also elsewhere?

**P4** (00:02:00): Well that's what I'm talking about.
Interviewer (00:02:01): Oh, I'm sorry.

P4 (00:02:02): Oh, sorry.

Interviewer (00:02:03): The group therapy . . .

P4 (00:02:04): Yeah, the group therapy was in a hospital.

Interviewer (00:02:06): I see, okay. And, um, so, uh, wh--what are the--and you don't have to get into anything too specific here--but what are the kinds of things that you speak to the therapist about or spoke to the group therapy about?

P4 (00:02:20): Well, um, I have a history of sexual abuse by my grandfather, um, so s--somewhat that, post traumatic stress, and then, um, I suffer from major depression and anxiety, um, but for the past I'd say 10 years, maybe less than that, I've been the primary caregiver for my mother, who had, um, dementia and they also said maybe some Alzheimer's, but I think it was more the vascular dementia. And, um, then a lot of physical problems that were going on, but I also, in the course of that, became estranged from my sister and brother. So, that was like an ongoing problem for me and--and a great stress.

Interviewer (00:03:15): Yeah, so, a--a lot of what you were t--touching on in therapy was emotional support for these many stressors that were going on? Okay. And, um--uh--ha--so--so, I understand that you've been using mental health for--for quite some time, correct?

P4 (00:03:36): Yes, unfortunately. [Chuckles]

Interviewer (00:03:38): [Laughs] Yes, so how does the care you're getting now, from--from any of those places, how does that feel different from experiences you had in the past?

P4 (00:03:50): Well, um, in the past, um--well, when I first started out, um, it was kind of hit or miss, because my parents were not behind me, really, getting involved in therapy. They're from a different generation altogether. And they didn't want people knowing that I was going to be in care. So, I actually spoke to, um, a woman who I was told by a professor of mine that sometimes people when they're not living up to their intellectual potential have psychological problems going on, so he wanted me to see her. And so I contacted her and at that point I was working, um, in advertising so, um, I contacted her and she gave me the name of this person, but it was kind of weird because it seemed like it was more he was interested in giving me meds and he couldn't see me regularly, so, um, you know, so it was mostly give me pills and then he wanted to do this hypnosis thing and so I said, "Well, alright, I'll try it." But, um--and it went--really, it was just more--more of a deeper, um, feeling and emotional, you know--touching your emotions more deeply. I was pretty much aware of what was going on, so I mean there was no way that he could have taken advantage or anything like that. But, um, so, then at one point, um, you know, we had talked about me going to this, um, live-in place in Litchfield, but when I spoke to the people there they said, "But you're working and really you should, you know, continue with that if you possibly can and just do, you know, outside therapy." So. So, that's when I think I got
involved with my--he was actually a psychiatrist and--slash psychoanalyst and I think [sigh], looking back on it, it triggered, I think, my post traumatic stress, because he was an older man and, of course, my grandfather was an older man. He also had this, like, walk down type of, um, office that I would walk down into and he had like this couch-type thing, but he didn't have me on the couch, he had me sitting up, but I think I just--because I started to get into, um--getting worse and I started, um, hearing voices and I started, um, seeing, you know--hallucinating and things like that and I was in and out of hospitals--into the hospital. So, I wasn't doing well at all, um, [pause] and, um, [pause] his type of therapy, which was that you don't even say hello to the person, that was not for me at all. It was just so impersonal. And then, um, he had other, you know, things that he--really wouldn't talk that much at all, he d--and he could sit there and sometimes I would just be--couldn't talk and I would just be looking at the floor and there would be silence for almost 50 minutes and so that was not really conducive to me speaking or feeling comfortable or anything like that.

**Interviewer** (00:07:38): So it felt like, in some ways, that that approach exacerbated some of--some of what you were struggling with.

**P4** (00:07:45): I think so, because, um, at one point I--I said to him, "Well, um, I think I really need to deal with"--I had been with this artist for a year and, um, I was in love with him. He was an older man though and he had gotten into, um, debts and everything and, um, decided he needed to go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided well that's where he was gonna go, but that just really hit me badly and, um, [pause] I just--that's when I kind of ended up, uh, in the hospital and--and--um, you know, when I tried to say, "Well, I think there's something here and I don't know--I'm not dealing well with his leaving" and all that and--but he just thought, "Well, there's nothing to do with that." And at that point he had, you know, said I was paranoid schizophrenic and, um, so then he was pushing all these heavy-duty tranquilizers and I kept telling him, "They're having a paradoxical effect on me." Which I didn't know at that point about paradoxical effects but I do at this point. So I'd say to him, uh, "I'm feeling worse and I'm feeling more anxious and more paranoid" and all this and he'd say, "No, no, no. You can't possibly, because these are supposed to treat that." And so, um, eventually--um--well, my parents and my father especially was very mad, um, about me continuing to see him and I don't know, I just was so sick and then I felt like, well if I give up on this then am I just being--you know, kinda wimping out and I'm not, you know--maybe I need to hear what he's saying or need to do this or--but, um, that finally--we ended, because we kinda got into this tiff with each other and, um, I had already started to--to ask about another therapist and that type of thing, so, um--and so that's--that--we did end and so that was probably the best thing anyways, [chuckles] so. But--but, I'm not--my present therapist, now--unfortunately, it's a clinic, so I've had to go through different changes with my therapist, especially, um, because they leave to do another job and whatever, so--and I have had a few that have been very good and unfortunately they've moved on, but this person right now, I don't know, we're kinda going through a--a weird situation where he's saying things or doing things that are just making me more anxious and . . .

**Interviewer** (00:11:08): Can you give me an example?

**P4** (00:11:11): Well, for instance, um, I've been having this problem with Department of Motor
Vehicles, 'cus unfortunately my insurance company, um, made a mistake and, why they did this I don't know, but the guy transferred funds I had already paid them to this new, lower fee insurance that we're going to start in October. But you don't take the insurance away from a person and make like we did-I didn't have any insurance, so DMV sends me this letter that I'm not gonna be able to register my car because, um, I didn't have insurance from June until October. So, things like that just get me very anxious and I'm never sure that I'm gonna be capable to, you know, take care of them and handle them and--well, so he--I wasn't able to get on to the website with this, um--we have a resident advisor whose really very nice and everything--for some reason we couldn't get on, but she decided to call the insurance company and see if she could get somewhere better with them, 'cus I thought I had solved the problem and everything talking to someone at the insurance company and apparently that may not have been the case, 'cus then she talked to someone and they did actually send us in an email exactly what they were gonna send to DMV and that other person hadn't done that. And I said to her, "Well, how come you could get somewhere when I couldn't? I don't understand it. I mean, I was very kind and everything and considerate" and--and she said, "Well, sometimes when it's not your problem, you know, you're able to, uh, do it better for the other person." And I'm just thinking that maybe they see that another person knows what's going on and so they better make sure that they correct the person. It's kinda like having a witness to what's--of course I have trust issues and so that's why I kind of get all upset about, well is this gonna be taken care of or not and all that, so, but.

**Interviewer** (00:13:28): So--so . . .

**P4** (00:13:30): Well, what he did, oh yeah, I didn't finish the [laughs]--okay, so what he did was, he gets on the website by some--whatever and, um, he goes, "Alright, give me your, uh, license and I'll pu--put in all your date of birth and your everything and." So he gets onto the website, but what it says is that I owe this penalty of 200 dollars. And I said, "What!" But I said, "Well, we just sent the proper things, so maybe the other person didn't send it or DMV is so behind", 'cus they changed over their computers and--but then he's saying to me, "Well, I think you should go down their in person." And I said, "How do you think I'm going to stand there for two hours, I can hardly stand"--I have a lot of arthritis pain. So, I said, "I can't stand for 15 minutes, so I'm not gonna be able to stand for two hours or more." Well, I called the resident adviser, because--I said, "Well, see now you've gotten me all upset about something that I felt okay about." So, um--and he laughs and he thinks it's funny. And he's--lately, he's done that. He thinks things are funny when I don't think they're funny. So. But anyway, the resident adviser said, "No, just wait and let's see, you know, if it gets taken care of and all that," so.

**Interviewer** (00:14:56): So, um--so, in--in terms of how he--so is his--the way he relates to you, is that quite different from how the previous therapists have related to you? Or spoken with you or?

**P4** (00:15:14): Um, well [sigh], I guess yeah, somewhat, now. I dunno what's going on with him or maybe he's just really in a Christmas mood and I'm just--this year, I'm not in a Christmas mood and I dunno. But, I kind of ended up with him, 'cus I was in the intensive outpatient there and I had been seeing this woman who I liked, but she had told me that she was taking on a different job there, so she wouldn't be able to see me every week. And I felt, um, because of my whole situation, my mother and everything still, um, that I needed to see someone every week.
So, that's why I ended up switching to this other therapist. And, um, [pause] for a while it seemed to work, but I dunno, it's just.

**Interviewer** (00:16:14): And so, um, let's see. Are there any ways in which the care you're receiving now is--eh--different in treatment from care you've received before? So--so, like, the intervening years as well, um, so after the psychoanalyst you saw, is there anyway the care you receive now is different than the care you received before?

**P4** (00:16:34): Well, yes. When I, um, finally ended up, um, going into--well, I ended up, um--after seeing him, I was with, like, a psychologist and then, um, he worked with a psychiatrist. So, I found I liked that interaction better and--you know, and he was a friendly person and he would say--actually say "Hello" and you know and all that and "How're you doing?" and so there was interaction and he would talk to me and not just me spouting off for 50 minutes and maybe an "mm" or an "ern" or something like that. And so I like to have dialogue and have someone give me feedback about what I'm saying.

**Interviewer** (00:17:23): Mh hm. Yeah. And so the--the--you've--the most--it sounds like most of the therapists you've worked with then have done that in a way that's felt better.

**P4** (00:17:35): Yes. Yeah.

**Interviewer** (00:17:37): And, um, are there--are there any--what other differences are there in the--in the style of approach between the experiences over the years?

**P4** (00:17:51): Hm. [Pause] Well, they started feeling that I should get into, um, Dialectical Behavior Therapy. Do you know what that--okay. So, um, to begin with what the--the first experience I had with it, um, most of us in the group felt it wasn't really helping us because they weren't showing us how it could relate to our own life and how we could use it in every day life. And, um, so I don't think I got so much out of that one. But then, I was at a hospital, um--outpatient though--and I went to their Dialectical Behavior Therapy and I was in that for about a year and, um, in that think, you know, she really tried to give us examples of how to pertain it to our lives and she'd give us handouts of different meditative styles and things like that and--and other types of, um, like art therapy and things like that that could help also. And, um, one of the things too--but unfortunately, um, she was in charge of my therapy, I guess, at the hospital and at the same time I had started, um, a grant with some other people to, um, research different trauma programs. And I wanted to put one together for--'cus at that time I was still in the Clubhouse. And so, um, I felt that they really needed a trauma group, um, but, um--and then when I was at the Institute with the DBT, I had said to this particular woman, um, "I really think that I need to be in a trauma program." And I said, "I've really never dealt with that whole area of my life." And so she at first was telling me, "Well, no, no. I don't think your insurance is going to cover it. And oh no." And I said, "Well, then can you find out if I can pay monthly so much, or whatever, 'cus I really think I should be doing that." And then, I guess she realized I was serious about this and so she went to talk to the, um--I guess the director. And he said, "Well, I'm not going to keep anybody out of a program just because their insurance won't pay, so"--but, she made it so I could only stay for--I don't know if it was eight weeks or something like that. And at the end of that, even the staff said to me, "Well, we were surprised at your having to leave or your going to
leave." And I said, "Well, it isn't my choice. She's saying I have to leave." And so it's too bad they didn't kind of try to say, "Well, look, she really needs to stay in this." 'Cus there seemed to be some kind of, unfortunately, battle there of who was gonna be in charge of the care or whatever. And, um, so that wasn't my intention but it ended up that way. So that was an unfortunate thing, 'cus I didn't feel like I could stand up and say, "Look, I really need to continue on with this. And so we need to figure a way out." But, I guess--because I knew that this was really triggering me and so I knew, therefore, that this was a needed, um, treatment and program, but . . .

**Interviewer** (00:21:59): So, it felt like your--your knowledge of your need was not being listened to?

**P4** (00:22:05): Right.

**Interviewer** (00:22:06): And have there been differences--and including the Clubhouse perhaps even--in how, um--or what differences have there been in how, uh--in how the--people in the care behaved towards you or treated you?

**P4** (00:22:28): Well, there was one time when I was doing--I ended up being the leader, which I didn't intend, but people kind of had me as the leader of the trauma research group. And at one point, I was taking one of the members home--giving him a ride, and he disclosed to me that he not only was a trauma victim, he also molested young kids. And that just really freaked me and got me triggered, because my own thing was of being a young child and being molested. So, I went to my, uh--I guess I, uh--the head of the, um, rehab area there, that I was in, and they were trying to convince me that no, I shouldn't say anything to anybody, because that might, um, upset this guy and, um, I should keep this under wraps. And I said, "But, that isn't fair to me, I mean." So finally, in one of our group meetings, um, I just--I said, "I'm sorry, but I'm not going to be able to not say this to everyone in this group and, um, you know, I'm sorry if this upsets this particular person, but I'm upset and I'm triggered and I need someone to help me with this and maybe some of the other people do also." So, we then had, um, a woman that worked in their emergency services and she actually was a, uh, trauma specialist, so she came into some of our groups, then. And then I--actually, after that I became her, um, one of her patients or clients, um, after that, so.

**Interviewer** (00:24:34): Mhm. And so, um, what differences have you noticed between the providers or professionals you work with now, compared with the ones you've worked with before? And th--so, not just in terms of, um, treatment approach, but in terms of how they've been with you as people.

**P4** (00:24:57): Well, unfortunately, I haven't had such a good experience as far as I was trying to go back to work, um, and I feel there I was not dealt a fair, um, option. Because, first of all, I had someone who kinda treated me like--well--an--well she would go into the interviews and I guess people didn't realize that I had the mental health background and she would just put that out first before they even met me . . .

**Interviewer** (00:25:37): And this was a co-worker?
P4 (00:25:39): No, this was actually a staff person who was supposed to be in vocational, um, services for people. And, um, you know, so at one point I said to her, um—'cus I had gotten to the place where we were going to interview and she wasn't there and I kind of panicked and "What do I do now?" And then it got to be late and it was almost time for the interview, so I figured I better just go in and then she all of the sudden flips into--what's--with her car and makes a turnaround and goes back out and I'm thinking, "What's going on?" And then she gets there and I said, "Well, what happened to you?" I said, "I don't understand." And she goes, "Well, if you were so concerned, why didn't you make the call yourself? You--you--you could make the call yourself." And I said, "Well then what do I need you for then, if . . . ."

Interviewer (00:26:36): What call was she talking about?

P4 (00:26:37): I shoulda made the call to this particular printer, 'cus I was in graphic arts and so we were looking into printers and different places like that for me to work. So--so, that got me upset, 'cus we're getting into a little tiff before we even get into the interview place. And then we go in and, um, I guess this particular woman didn't know that I was coming with her. And so she kind of, like, looked at me like--you know--this look like, "What're you doing here?" And so that got me even more, you know, within myself and I thought, "Oh gosh." And then, um, so she took, you know, the vocational person in and talked with her and then, you know, she came out and then she was warmer and she offered her hand to me and said, "Well, come on in." And most times, when the people did meet me, um, you know, they seemed to find something that they would, you know, um, say that was good about my artwork or this or that. Um, but at that point they all wanted me to know the computer, which I had never gotten into, so. The thing was that they had had--you know, I said, "Well, could I do an internship?" And they said, "Well, no, because we've had people in the past and it hasn't worked out." So, um--and also with vocational services, I found the same type of thing where they kind of were looking down at a person with a mental illness and not giving me a fair--fair try at things and--and that type of thing.

Interviewer (00:28:29): And in the mental health care you received, have the--have different providers behaved differently towards you?

P4 (00:28:39): Um, well, yeah. I had--when I was in the intensive outpatient, um, they had brought in a new psychiatrist who, um, was supposed to be for the particular group I was in, so he was not my regular psychiatrist. And there was a certain medication that I was using and he just was against me having it and using it. And he said, "Well, no, no, no. You're going to be going off of this." And I said, "You will give me no quality of life, then," I said, "and I don't think that that is fair." And so he was sticking to his guns and he wasn't, you know, wasn't going to give me the refill and then I guess the pharmacy said, "Well, this is not a medication you should take her off of, you know, just like that." And, um, you know, so he said to me, "But I thought we agreed." And I said, "But I didn't agree to go off of it like that, completely. And you said we could try going down on it and I agreed to that but I didn't agree to not at all." So, I got pretty upset, crying and stuff, to my, um, regular psychiatrist and he said, "Well, do you want me to speak to him?" And I said, "Well, I don't know that that's a good idea." And I said, "I don't know." So, finally, this new psychiatrist said, "Okay, you know, um, I'm gonna allow you to stay on that medication." And--um--and he said, "Because you said to me, well, it would affect your
quality of life and so, um, you know, you can stay on that, so." But, that put me through some trauma for a while, um, and now, again, this psychiatrist is telling me that I really should get off of that medication, that it's been linked with, um, Alzheimer's and that type of thing. And--um--but in--in doing this--um, it was after my mother died and I'm really not in a good place at this point and so I finally, when I saw him again, I had, you know, tried not using it and just using it sparingly and all that and then I said to him, this past time I saw him that, um, I said I would sign something, you know, releasing him from any, um, responsibility of anything, I said, but I don't think I can completely do without this or having it available if I did need it or whatever. And so he said, "Well, you don't have to sign anything, I'll just put it in your chart." And so.

**Interviewer** (00:31:43): So, that--you have, sort of, across the whole time you've received mental health, have had providers, um, push you to do things that you weren't necessarily comfortable doing with medication.

**P4** (00:31:59): Yeah. Medication has not worked well for me, um, even now, um, it seems that, well the medication I'm talking about, which, um, is Lorazepam or Ativan, and I've tried to explain that that seems to put me in a more--I don't know, maybe less depressed mood and more, um, wanting to live and wanting to--and be able to, um--um--I dunno, I have a great fear of people and I--I feel that goes back to my trauma and it wasn't only that trauma, with my grandfather, but I think that was the biggest one. And so I have a fear of people and so where other people would--would gravitate to people and, you know, want to seek them out and talk to them, [tearful] I'm not--I can't always do that, especially if I feel in a really depressed, um, way and I just can isolate myself and not reach out to people. Of course that's my upbringing too. Um, my father was a big one for, you know, not telling people your bad things and just being upbeat and good. And, I mean, to an extent I have incorporated his--um--his need for humor, because I do use humor a lot of times to--um--kind of the opposite of what I'm feeling and so I'll seek out maybe a TV program that's funny and, you know, use, um, humor to kind of help me out. [Tearful] Sorry. We have no Kleenex. [laughs]

**Interviewer** (00:34:03): I know. Stay right here, I'll get you some.

**P4** (00:34:05): Alrighty, thank you. [Interviewer leaves the room and returns] Oh, thanks. Oh, thank you.

**Interviewer** (00:35:15): So, that's something that's continued to be difficult for you.

**P4** (00:35:18): Yeah. [Pause] And in fact at one point in my life--um--and I didn't realize it was related to the trauma until I went into the hospital's trauma group. Um, I started cutting and I just couldn't seem to stop myself. I was using razor blades and then, at one point--'cus I was a biology major in college and graduated with a biology, you know, bachelor of science degree and so then I was using a--the, um, scalpel and all that. And then my father found that out and he took that away. But, um, it seemed I couldn't, uh, stop doing it and I just hated myself and I would burn myself and--well at one point I used our electric carving knife on myself. And I just really hated myself and at that point in my life I was blaming myself for the whole sexual thing and I thought I must have done something to get my grandfather to do that. And so of course in the trauma group I learned that wasn't the case, but--um--but it wasn't until I started taking care
of my nephew, [tearful] until he went to, um, kindergarten--um, he was a baby, my sister had him and her first husband, who she's divorced from, and, um--but she was going back to work and at that point I wasn't workings, so, you know, she asked me if I'd want to take care of him and I said, "Alright." And, um, so I just really felt close to him and he felt close to me and it was love I needed and, um, [tearful] I stopped cutting at that point, um. And it wasn't until I--I, at one point, I guess, was in--I dunno if I was at the In--um--Intercommunity, they had finally put together a trauma group there and--even though they kept fighting us about that and, uh, I said you've got recidivism even though you don't do, um, trauma work and I think you need to address the trauma part of it or you're still gonna keep having people with recidivism and all that. So, um, I finally went to their trauma program, but then at one point, I needed to call my therapist who was the trauma--she was, um, very knowledgeable in trauma and I said to her, "It's been years and I haven't felt like cutting, but I feel like it know." And so she said, "Well, I think it's the trauma work," and she said, "if you really think you can't stop yourself, than you need to go to the hospital, but if you think maybe you can, um, do some journaling or something like that to get yourself away from feeling like that"--so, luckily, I was able to not do any cutting and so that, hopefully, is, you know, the end of that I hope, but, um, I guess you always have that fear of not knowing what will happen, but.

**Interviewer** (00:38:54): And how do you--how do you feel, um, these providers over the years have--have there been differences in how they have treated you emotionally or have they have spoken to you?

**P4** (00:39:14): Um, yeah, I think so. Um--um [pause], like some of them, you know, keep a dialogue and will kind of talk to you about, "Well, okay, you said that, so I see how that relates to that," but, I haven't had all that many who have been that astute or whatever you want to call it to, you know, do--do that type of thing. And, uh, as far as like doing the trauma part of it, I feel like that's still something that needs to be addressed and I don't feel like I'm with a person that I would do it with. So, um.

**Interviewer** (00:40:07): So, some of your needs are not met in the care.

**P4** (00:40:09): Right. Yeah.

**Interviewer** (00:40:11): And--um--and in terms of the recovery oriented approach to things, have you--what differences have you noticed with regards to that?

**P4** (00:40:23): Well, I don't have, um, addiction as far as drugs or alcohol, that type of thing, um, I do over eat though, but--um--and that's not good, I'm not saying it's good, but, um, [pause] you know, a--I think some have, um, encouraged me about, like, trying to pursue my art and all that, but, I dunno. I've always found it hard to, um--even when people have been artists themselves and they've looked at my work, I've still felt like, well, they can't be telling me the truth, you know, they're saying it's good but how do I really know and I just kinda doubt myself and all that. But, I mean, you know, they've tried to build me up and, um, tell me positive things, but, um, well, to go back to the very first--well, one of the first, um--the psychiatrist that I was with for about ten years, um, at one point he said to me--and he said it to my parents to, he said, "I, you know, get her feeling better about herself and then she comes home to the family life and
she's down again and being taken down," and he said, "that's not working to help her." So.

**Interviewer (00:42:02):** So--so, le--le--tell me if this sounds true to you. So, it sounds like--like, mostly, um, across your experiences, even with some differences in technique or approach, mostly you feel that people have, uh, treated you as a person similarly.

**P4 (00:42:24):** Um, well, some--some are--um--well, not with the, uh, vocational part, I don't feel.

**Interviewer (00:42:36):** Okay.

**P4 (00:42:36):** Yeah.

**Interviewer (00:42:37):** So, c--can you tell me more about that?

**P4 (00:42:39):** Well, I was with, um, one employment support person--and, um, it wasn't just my opinion of what was going on, but it was other people that then saw what was going on and she was like putting all these stumbling blocks in front of me and, um, they were, like, helping me to go to school--go back to school for the computer and for, um, graphic arts and also for, um, multi-media. So I have like an Associate of Science from a community college and that. But she just--for some reason, um, she would send me to the financial aid people with the wrong information and the wrong dates and all sorts of things like this. And they'd say to me, "Now she knows what to do, I don't understand what she's pulling here." And one time--and at this point I would have the person who was supporting me through my, um, education part--I would have her sit in on my meeting with my employment support person. And at one point, she said to me--and now, she's the one that gave me the wrong dates and everything and the guy at financial aid said, "Well, I have to wipe this out and I have to put this down as the date, otherwise you're gonna be going back and forth here with this paper for no reason." And I said, "Well, you better initial it or something." And so, when we got into the meeting with her, she goes to me--she's like looking all the sudden at me and with this smile and she goes, "Well, now you're an artist," she goes, "so what's to stop you from whitening this out and putting in a different--writing something different in there?" And the woman, um, from employment support said to her, "Why on earth would you say that to her? That doesn't apply at all." And she goes, "She's never done anything that's been underhanded or, you know, not decent or honest." So, finally, after having humiliated--humiliating things with her, I finally did switch with the help of, um--an advocate came in and we talked with her boss and I just switched to somebody else. But then, I came across this woman that was supposed to help me with updating my, um, resume. And for some reason, I don't know what was going on with her, but she would call me--like I'd be there on time, I'd be sitting in the waiting room and it was obvious there were a lot of people, 'cus they would talk about it and think it was real funny, that they had been incarcerated and, um, in jail. And maybe that's the only people she was supposed to be helping with the resume, 'cus they know, she'd come out late for our appointment, she'd call me in and then she'd say, "Well, you know, uh, we only have so much time." And I said, "But I was here on time." And she goes, "Well, we only have, you know, five more minutes," and she said, "I really don't have time for this." And I thought, "Well who do you have time for then?" But I didn't say too much because you feel like they're in the power and they can do what they want if they so desire, I mean.
Interviewer (00:46:24): Have you felt like that on the mental health care as well or only on the . . .

P4 (00:46:28): No, I have at times with mental health. I felt like, well I don't want to end up in the hospital, so I better not say anything, you know, about this or that. And, um . . .

Interviewer (00:46:41): Can you tell me about some of those experiences? You don't have to go into detail you aren't comfortable with, but.

P4 (00:46:50): Well--and this turned out horrible, but, um, it was--I was going through school and my mother was--was like at this point really going downhill. She was still at the house, 'cus I was able to keep her there and I was there, um, but she was very angry, very negative with me, as she always was--and that I was like dirt under her shoes, even though I was, as I was told by everyone else who saw the situation, I was the one keeping her able to be at home still. And I didn't realize how badly she was going downhill as far as emotionally and mentally. Um, my father had already died, um, and so at one point I must have said something about, "Well, I feel like harming myself or I feel like sometimes, you know, um, my mother is just so nasty and horrible to me and I could just give her a little push or something." And--but I never, ever had or ever would have, but unfortunately I said that to someone and so then they felt like they should bring in Senior Protective Services--I don't even like saying this, I'm sorry. [Tearful] I wish I hadn't said it.

Interviewer (00:48:16): It's okay, it's okay, it's okay. You don't have to talk about it.

P4 (00:48:19): [Tearful] But this man found--let's just put this to rest though--this man found I hadn't ever hurt my mother and I never, ever would hurt my mother. So, there was a case where I never should have said anything, because then it got blown out into, um--and in fact my mother was the one that slapped me and--and used to, with my brother and I, with the stick--about--whacking us on the legs and stuff.

Interviewer (00:48:49): So, you--you've had experiences where, if you spoke freely, things were misinterpreted and so the worst was assumed.

P4 (00:48:58): Right. And then my brother got into that kind of thing, um, when I asked him for some help, 'cus he was out of state and so was my sister. And my mother was--I was still trying to keep her at home. But at one point she tried, between the time I was still at school and I got home--and we had homemaker's there and companions and stuff, but, um, the person had left and my mother dragged a chair and, um, you know, was going to try to get up on the chair and fix something on a curtain. And I said, "Mom"--and then I get home and her leg is all bleeding and everything, 'cus she had thin skin and all. So, I finally--I said to my brother, "What are we gonna do? Wait until she--" I said, "her--her judgment is not--is off." And I said, "Are we gonna wait until she breaks a hip or breaks something or worse." And--and so then, you know, he was all annoyed with me and how dare I ask him for help, so then he started in that, um--um, when I tried to say to the--the agency, well I need to take my mother to get her hair done or I need to take my mother to a doctor's appointment or something, so they--then I had my brother or my
sister-in-law call me up and say--well, not my sister-in-law, she wouldn't, but she had my brother calling and saying, "Well, where do you think you're taking her?" And I said, "What do you mean?" And he goes, "Well, um, you have to get my okay or my wife's before you take Mom anywhere. And it should only really be to take her to, um, a doctor's appointment or to get her hair done." And--and finally after him doing that kind of stuff and then having people watching me or not watching me and what I was doing or not doing, I finally said to the people at that agency, "You tell her son to call his mother and tell her that. That she has to get his permission or her daughter-in-law's to go, um, out with me, uh, for whatever it is." Uh, so. It just became horrible.

Interviewer (00:51:15): Yeah. Yeah. Well it--sort of going back to the men--mental health care that you received . . .

P4 (00:51:27): I know, maybe I'm getting off on . . .

Interviewer (00:51:29): No, it's okay. That's--it's okay to go off a little bit too. [Laughs] But--but, um, how--let's see, um--what's the best way--I have to try to figure out what the--asking the questions in the best way is tricky, but, um. How does the mental health care you're receiving now, how does it make you feel about yourself? The way they sort of interact with you and, um, speak with you and . . .

P4 (00:51:57): Yeah. No, this guy is not--is not, uh--I dunno what's going on, um, he's just--unless it's just that I'm more depressed now than--and I'm not finding any levity in--but some of the things that he's finding funny, I'm just am not finding funny. And I guess he's maybe just nervously laughing about something, but. So it's not, um--and at one point I, um, was trying to do this thank you card design for, um, this woman and she had--we had started before my mother died, so it was like in maybe May or June that she asked me about doing it and so I had a design that I was gonna use and everything, but--um--and she wanted me to bill her before the end of June so that it would be that fiscal year. Um, but then I got behind on the card and so, for instance, you know, he was making fun of me about that--that instead of understanding that, okay my mother then died--and even though I had her in hospice at that point, I didn't expect her to die at that particular moment and day. Um, 'cus that weekend she had been--which was July 4th--she had been in--pretty well and still knew me and all that, so I hadn't expected her to--to die and, um. So he was kind of like, "What do you mean, you got paid for it and--and now you're not doing it." And I said, "Well, if I can't do it you can be sure I'll give her her money back." But, I said, "She wanted to be billed and," I said, "in fact, I've spoken with her and she's been very kind and very understanding and she said, 'You just take care of yourself. And promise me you will take care of yourself. And whenever you can get the card done, then you get the card done.'" [Tearful] And you can see that this is not helping me--um--I'm not trying to talk to you about you, I'm talking about this man that I have as a therapist now. So it's not really helping me when I leave there and then I feel like, well gosh, uh, I know I feel bad about not having gotten it done sooner and all that, but."

Interviewer (00:54:30): And the psychiatrist you see, how--how does--the appointments with him, how do they make you feel?
P4 (00:54:36): Well, unfortunately or fortunately, uh, psychiatrists--I feel like sometimes they don't think before they talk, because, um, I don't know what it is with them--well now, they don't see you that often anyways, so they don't know a lot, but he seems to take more of an interest in what's going on than just prescribing the pills. But, recently I was, you know, talking to my, um, therapist about it, and I said--you know here I'm talking to him about going on a different antidepressant and he's saying to me, "Well, you're going to feel--one of the biggest things is you could feel, um, nauseous for at least two weeks or more." And I said, "Two weeks?" And he goes, "Well, uh, you know, uh, say you have twenty years to live, uh, two weeks out of twenty years is not a big thing." And I just kinda looked at him and he goes, "And besides--" he goes--and he gives this little grin, which he doesn't usually smile, and he goes, "And besides, most of the people, uh, can stand losing weight," he said. And I just kind of was like, "Yeah, if you had to take these psychiatric drugs, I don't think you would necessarily stay thin, 'cus they do increase your appetite and everything." So, I just thought, well that wasn't very kind and . . .

Interviewer (00:56:09): So, it's--you're not always communicated with in a way that feels kind and respectful.

P4 (00:56:14): Right. Right.

Interviewer (00:56:15): Yeah. Yeah. And so, those interactions with the therapist and the psychiatrist, how do those affect how you feel sort of about the world around you in general?

P4 (00:56:33): [Sigh] Not very good.

Interviewer (00:56:34): Yeah. I can understand that. When you were involved in the Clubhouse, um, was--did that change how you felt at all?

P4 (00:56:49): Yeah. For a while, um, I really felt, um, you know, connected and seemed to be liked by a lot of people. And in fact I became like a volunteer leader and things like that, so, um, most of my experiences with the Clubhouse were good.

Interviewer (00:57:09): Those were positive. And what made you step away from that?

P4 (00:57:13): Well, because, um, I think I was going back to school . . .

Interviewer (00:57:18): Uh, how long ago was this? Sorry, just for my reference point.

P4 (00:57:21): Um, well, 2001. I'm thinking, yeah, yeah. So, um--and it just wasn't really meeting my needs anymore. Um, I hadn't gone back and, um, well I--I don't like to put people in categories, but it seemed that it was more for, um, well less highly functioning people. Um, kind of a place that they could go and--and be and--and, um . . .

Interviewer (00:57:57): And it felt like you were fitting in less with the community there?

P4 (00:57:59): Right, yeah.
Interviewer (00:58:02): But the--it sounds like there were some aspects of it which made you feel a little bit, um, stronger and more connected as well.

P4 (00:58:14): Yes. Yeah, yeah. I think the Clubhouse was, um, helpful to me and--um--you know, I think clubhouses are helpful. But, I--it seems that now they're starting to get away from like the old, uh, clubhouse model or whatever and, um, I think there still is a need for that and, uh, you know it's more now that they want to do, um, groups and not so much that they'll help you to go out to some nice things. Like, we used to do a lot of different things that I probably wouldn't have gotten to do and for--at that time, they only managed to pay five dollars and what they did was they kind of put that into a pool of money and so they would pay the rest of--like if we went to a movie or something like that. So they made it very affordable and they don't do that now. It's one major outing that they do and they don't do the weekends like we used to do. Because a lot of people, I think, on the weekends can feel like at a loss and "What do I do?"

Interviewer (00:59:26): Yeah. Yeah. Um, has your experience been that there--um--there's sort of a gap in services once you reach a certain level of functionality?

P4 (00:59:41): Yes. Yup. Um, in fact I have some friends that we've discussed that. That it's too bad they don't have some kind of a graduation type, um, other group. But I guess they expect that you'll get together with those friends or whatever and do your own things and. But it might be, you know, a nice thing to have somebody that, um, that was a staff too, in case you wanted to bounce certain things off of them and stuff. I mean, I find having a resident advisor--um, I live in subsidized housing, but it's mostly for elderly. But there are a few of us that are, um, younger and disabled or whatever. And the resident advisor is a very kind person and so I feel less alone because I can go to her about different things that come up, you know, financially or just, you know, um, housekeeping type things or whatever.

Interviewer (01:00:49): Right. I see. So, th--that's sort of--a--w--those are the main questions that I have, is there anything that we haven't touched on that you think would be important for me to know or anything you'd like to share that I haven't asked about? With regards to those experiences or your care?

P4 (01:01:16): I don't know, I don't think so.

Interviewer (01:01:17): Okay.

P4 (01:01:18): I just hope I answered your questions though.

Interviewer (01:01:20): Yeah. And I--I know that was a difficult conversation for you, so I hope not too much.


Interviewer (01:01:31): Um, and so I just have a few last, um, demographic questions to make sure I . . .

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Interviewer (01:01:38): So, um, how old were you when you first entered care?

P4 (01:01:41): Oh, gosh. Um, probably like 19.

Interviewer (01:01:45): Okay. And how old are you now?

P4 (01:01:48): 64.

Interviewer (01:01:50): Alright. And h--um, if possible, can you recall the number of places you've received care between then and now?

P4 (01:01:59): Um. Well, first I was in private care, um, then I was, uh--there was a hospital. I was at that hospital a couple of times. And then the clinic now. But before then I had been in kind of the private sector. So, um, uh, for the last, um, at least 10 years I guess, I've been at a clinic.

Interviewer (01:02:31): Okay.

P4 (01:02:33): A hospital.

Interviewer (01:02:35): Well, great. Thank you so much. Um.
Appendix F: Participant Narratives

Participant 1: Thomas

In 1983, when I was 23, I had a nervous breakdown and the company I worked for sent me to see a private psychiatrist. I started attending a partial hospital program around 1989 and was there until 1993. They had a psychiatrist there and he would prescribe medication and then I would go to what are called "groups," which are activities, within the building. The partial hospital program was a place where you're kind of recuperating. It was kind of a dark time for me, the partial hospital. It was rough. We did chores there, which I guess were probably designed to help you in your recovery, but it was difficult. One of the chores was being assigned to the culinary unit at the partial hospital program. That's where I first got involved with cooking. At the partial hospital program, we had what was called a "consumer council," with a president, a vice president, and stuff like that. I was president of the consumer council at the partial hospital program for a while, so I would sort of run meetings with the patients there. Clients, I guess they call them now, more than patients.

The psychiatrist at the partial hospital program came from the prison system; he was very stern and he had a bad temper. So, it was hard working with him. One of the things that came up when I was in the partial hospital program was that they put me on some medications that didn't agree with me. When I asked to be changed to something else, they didn't listen to what I said. They disregarded my input and so I struggled for a long time with side effects from the medication. Sometimes the other staff at the partial hospital program did not listen to my needs, requests, or advice. For example, there was one time where I was hearing voices and I was talking to myself. The staff interpreted that as me not being able to drive home, so they took my keys away and wouldn't give them back. I told them that I was going to go to the police station to complain and ask the police to have them give my keys back. What instead happened is that I got taken to a psychiatric hospital. So, that's one example.

Now, I see a psychiatric nurse who prescribes my psychiatric medication. I've worked with the psychiatric nurse for 15 years or so. When we meet, she goes over my symptoms and how I'm doing. Sometimes I talk to her about a problem that I'm having. But it's usually limited to 15 minutes and then she'll say, "Well, okay, we'll continue with the medications, don't make any changes." The psychiatric nurse I see now listens very carefully to what I say, and luckily the medication seems to agree with me.

Once I left the hospital, I saw a neurosurgeon, acupuncturist, and psychiatrist. And then I joined a clubhouse that's based on the recovery model of Fountain House. Between 1993 and 1994, I was going to cooking school and working part time with my father in electronics. I have a Bachelors of Science in electrical engineering, so I was working as an electronics technician for the same company that my father worked for. I probably could have worked there full time, but they went out of business. I think another company bought them out and then they moved out of state. So, around 1995 or so, I was at the Clubhouse on a stipend. And then in 1998, I think that's when I was formally hired as staff. Now, I'm a chef at the clubhouse and I help run the culinary unit. The Clubhouse focuses on work readiness, being responsible, and being independent. In the partial hospital program, I was more a patient. At the Clubhouse, I'm an employee. But at the time when I was in the partial hospital program, I think I needed it. The thing that was the most helpful for me was when they came out with the medication Zyprexa. That was kind of a turning point for me, because before that the medications that I took had so
many side effects that I wasn't really doing very well, mentally. Then when I joined the Clubhouse, I was glad to earn some money and be more independent. That feels good.

Some of the staff that I knew at the partial hospital program moved over to the Clubhouse. The director of the Clubhouse was one of the people who had been at the partial hospital program. So, I had to sort of prove to this person that I was ready to go back to work. The director of the Clubhouse who had come from the partial hospital program has retired now, so there's a new director. The former director was geared toward the rehabilitation model whereas the new director is definitely recovery model-oriented. The old director was the sort of person who likes to be very much involved in running things and directing people. The new director more just sits back and lets you take over. She relies on my supervisor if I have any problems or questions. The two directors had very different personalities. The personality of the first director was more dictatorial. She was more emotional, sort of hot tempered, and she could get very angry. She had a way of making me very uncomfortable when I did something wrong. She would raise her voice and she had an angry tone. She just had a way of making me feel small I guess you could say. The current director is sort of like that too, but in a different way. She's a "manager-type." They were both "manager-types." The current director definitely wants to keep things running smoothly and she wants to be authoritative.

You have to be authoritative, because sometimes the clients will disregard what you tell them, unless you tell them in an authoritative way. The staff at the partial hospital program and at the Clubhouse are very similar in the way that they approach things. They know how to talk to people with disabilities. I think that the staff at the Clubhouse are better suited to the Clubhouse and the people at the partial hospital, some of them were not well suited for working in mental health treatment. They weren't sensitive to the clients. At the Clubhouse, they're more sensitive to our needs and so forth. Although in both places there is kind of a dictatorial side to it.

We have people at the Clubhouse that do things they aren't supposed to. For example, there's a designated smoking area and sometimes they won't use it and they'll throw their cigarette butts on the ground. So the director will have to say, "Well, you know, if you throw your cigarette butts on the floor or near the building, the building could catch fire." Some of the people have to be told, because there's a wide spectrum of people in different place in their recovery. And they have to sort of disciplined, somewhat. At the Clubhouse, they set up what is called a "rules committee." They committee has what they call a "matrix of rules." In the past, they had a system where if you broke a certain rule, then there was a certain consequence. The first consequence might be suspension for a day, and then maybe it would be a week or a month, and then the final consequence would be permanent suspension from the program. They did that for a while, but then a recent development is a new system where the person would have somebody counsel them about the problem and they're shown ways that they could do things differently so that they wouldn't cause problems. I don't know if it will work yet, because they just changed over to the new system. I think there's a few people at the Clubhouse that maybe will not respond. But, there's a lot of women in the program and I think that the women might respond better. I have a feeling - just a hunch - that the fact that there isn't a punishment for their behavior, will make some people more comfortable. Instead of a punishment, they are actually advised as to what to do.

So, staff at the Clubhouse have to be able to handle that type of client. They have to be able to direct them and help them, show them what to do. And they also have to have a patient side; when they're trying to teach something to a client, they have to be very patient with them and work with them, supervise them and show them what to do. Staff at the Clubhouse are able
to be patient with clients when they need to be. The staff aren't so patient with me, but with the other clients they are. The staff expect more out of me, because I'm an employee. At the Clubhouse, I'm expected to be a competent employee. I'm what they call "peer support staff." So although I'm a member of the Clubhouse, I'm first and foremost an employee of the agency. It was a big transition to go from "patient" to "employee."

Usually, when I talk to the director of the clubhouse, it has to do with work. I have a supervisor, and sometimes I will talk to her if I have some kind of problem. But, the emphasis of the clubhouse is on work readiness, so they don't really have time to discuss my personal problems. I'm not necessarily supposed to talk to the peers about their problems, but people sign up to volunteer for different work units at the Clubhouse, and when they sign up for the culinary unit, I kind of supervise them. They have to be shown what to do and in the process of working with them, sometimes they will talk to me about their problems and I will discuss it with them. But I'm not really supposed to do too much of that, because it's distracting from the work that I'm supposed to do.

The culinary unit prepares lunch for the Clubhouse each day and there's a lot of responsibilities that I have besides preparing the lunch. I plan the menus and do the shopping and when we have parties, I help to plan them. There's a lot of work involved. I typically feed around 24 people a day, though now it's kinda dropped off some days. The culinary unit has a very tight budget. We get a lot of food from a co-op of sorts. What happens is that different restaurants and, maybe, supermarkets, donate food to them, surplus foods or foods that they don't want. And we get it for a reduced price, sometimes for free. The food that we get, I don't feel is healthy. I'm kind of a vegetarian myself, but it seems to me that the clients are more interested in meat and so we serve a lot of meat. I feel like the meals that I'm preparing are not really the healthiest meals, and I feel that what you take into your body has a lot to do with how much you recover. We don't get as many fresh vegetables as I would like and I have to really cut a lot of corners when I'm preparing the lunch. So, I feel like I'm feeding them, but at the same time I feel guilty that I'm not feeding them the way I would like them to be fed.

I used to have a therapist, but now there isn't really anybody I could talk to in depth about personal problems. I stopped seeing the therapist about 15 years ago. For the most part, I'm okay with it. I'm currently living with my parents, who are aging. I'm trying to come up with a plan that will allow me to keep my entitlements and inheritance. I'd like to continue living in the same home when they pass away. In the past, I might have talked to a therapist about something like this. Now, I think I'll probably talk to a lawyer. What I'd like to do is plan the estate so that I can keep the inheritance and keep my entitlements. There's a law firm for seniors and the disabled and they have people that do estate planning. If I could get connected with them I think that they could probably help me manage my finances and also advise me in times where I might come into some sort of legal trouble or something. That happens a lot with disabled persons, they get into all kind of legal problems.

I also used to have a case manager, but now they have something called a community support program instead. In the past, if I had an important question, I would call my case manager. The case manager I had in the past set me up with my entitlements and would make recommendations for services, like a good dentist that took Medicaid. That's how it was in the past. Now, I could try contacting the same person again or I might try to directly contact an agency. I think that I don't need as much outside support as I did in the past. It feels sort of good, in a way, to be self-sufficient. But at the same time, I think that once in a while I might run into a problem that I can't handle and that I might want to discuss it with someone. The only people I
could talk to now would be my parents. Or I might look on the Internet and try to find a phone number or email address to contact someone who might be able to help. My former case manager gave me the number of someone in the Department of Social Services that I sometimes talk to, but she's very hard to get ahold of. It's not really clear who can help in an emergency anymore, but that feels okay, most of the time. When my parents pass away, it's going to be a shock and a big change. I don't know how I'm going to handle it. I could have a relapse. It causes me a great deal of anxiety.

I feel like I'm in a safe place where I am. I feel more secure at the Clubhouse. I think that if I were to leave that environment and go out into the community, I might be treated in the same where I was before, where I was put down. Or maybe, if I was in a situation where I was having some kind of psychotic symptom, people might not understand what's going on and there might be some kind of serious consequence to that. I think my work readiness is better. I think I can work better now and my symptoms are more under control. So, from that standpoint, I think that I'm more ready for work. I think that my confidence comes from within myself. I don't think that the program gave me confidence so much, but I think that the program gave me stability.

I had been laid off from a number of engineering jobs prior to coming to the Clubhouse. The company that my father and sister work for hired me right out of college. I had a nervous breakdown while I was there. That's when I was hospitalized in the partial hospital program. After I left the hospital, I saw a neurosurgeon, acupuncturist, and psychiatrist. I felt like I was well enough to work as an engineer again. I started working for a company and I was on a probation period, they were trying me out. At the end of that period, I didn't live up to their expectations, so I was laid off. So, I was coming from a place, before the Clubhouse, where I felt like I wasn't succeeding in my work.

I am more independent now. In the past, I was dealing with more symptoms and just trying to function and I think that I've moved beyond that. I went back to school and got a culinary arts certificate and got involved with cooking and I found that the work was not only financially lucrative, but it also helped me in terms of my symptoms, keeping busy and not thinking about my problems so much. I feel like I have a marketable skill as a chef. So, I feel like if something happened or for some reason the program closed or if I was laid off, that I could get work as a cook. So there's a sense of stability and security. I like the people that I work with there. I did have some trouble when I was working outside of the Clubhouse. Some people, when I disclosed my illness to them, abused me. People, for some reason, put me down, because I had a disability. The Clubhouse is a very safe place. For the most part, people understand where you're coming from.

I do get a sense from the staff at the Clubhouse that my disability does limit my work ability somewhat. I feel like I'm running up against limitations, in terms of remembering things. So, I have to try to write everything down because when they give me a lot of information, sometimes I can't remember it all and then sometimes I will forget that I had to do certain things. So, when that happens, sometimes I get criticized. They do a yearly evaluation of me and my evaluation was near the top, like most of my marks were the highest possible. I feel good, I feel like I'm doing a good job. However, I do feel somewhat limited by my disability. I'd prefer that maybe the staff not be so judgmental or critical when I make a mistake. But, at the same time, I think they're trying to create an environment where you experience what you would in the community, if you had a job out there.
Participant 2: Leah

I've just reentered therapy after a hiatus of two to three years. I reentered therapy because I'm still dealing with residual post-traumatic stress and fear related to some health situations. As I said, I've had multiple, multiple, multiple, uncountable traumas in my life. Sexual traumas, losses, hospitalizations and treatments that were not good, and I've been in two fires. I just keep running up against the trauma. I seem to get over it and then something else comes up in my face and brings it up. I have screaming nightmares. I said to my partner, who's very low-keyed about the whole thing, I said, "Honey, do you think I should go see somebody?" He'd never said yes before, but this time he said, "Yeah, I think so." He's wonderful. I will say, I went to therapy not knowing if it was gonna be a good match. It absolutely is. It's just a joy. The therapist has a private office, but the office was on the third floor, so she agreed to see me in a home office that was more accessible. She and I are just on the same page. We seem to enjoy a lot of the same things, we both love photography and music. She has her photographs all around. So it's just so fun and she's so non-labeling. I don't even see the DSM sitting around her office, which I like. I also see an independent psychiatrist who works outside of town. I only see the psychiatrist about every three months. I can always call her, but I'm not dependent on her in any way. We just get along well and I respect her and she respects me. She let's me guide how things are going to go. I've been working with her since about 2011, on and off.

I began working with her after all hell broke loose. It's hard, but I'll be succinct, because I've gone over this a million times with the team at my work and they gave me wonderful support. I had been doing really well and then all hell broke loose. I was beginning to thrive when I got hired at a local mental health advocacy organization. I have a background in oral history, writing, literature, and social service work. I had a psychiatrist who I had seen for many, many years. And I trusted him, as one would. This was back in the days when psychiatrists would spend more time, rather than just doing medication, but that was beginning to shift. Anyway, I completely trusted him. Then all of the sudden, he started saying that he wanted me to call him by his first name and then he would make little comments like, "Why don't you color your hair like all the other women. He started getting flirtatious, but I kind of brushed that off. I've had four joint replacements and I was having terrible pain after the most recent knee replacement. I had very good support at work; they allowed me to work from home when I got better enough and allowed me to adapt my schedule. After the surgery, the surgeons had cut off my pain medicine and dudda dada da. When I was able to start walking a little bit, I'd walk him to the door and out to the parking lot and he'd give me a bear hug. Well, the bear hug started getting nuzzle-y in my neck, and close, and pressing. I also became suspicious about the pain medication. The situation evolved. He had been saying to me, "I believe in pain control. I really believe in pain control." So he started coming to my apartment. To begin with, it was very professional. He'd give me the pain meds and dudda dada da. When I was able to start walking a little bit, I'd walk him to the door and out to the parking lot and he'd give me a bear hug. Well, the bear hug started getting nuzzle-y in my neck, and close, and pressing. I also became suspicious about the pain medication. The situation evolved. He had been saying to me, "I can't imagine life without you" in our appointments. I mean, it was getting out of control.

After a time, I became fully aware of what was happening. I did a lot of god-awful reflection and "what the hell do I do" and "who do I turn to." I went to visit my family and spent most of the time holed up in my room crying. They didn't know exactly what was I was doing, they thought I was just reading or something. I mulled it over a lot and I got enraged. I said, "This is really, really bad." I realized I had to do something and I came home. I did have a therapist at the time, thank God almighty it was a woman, and she knew the psychiatrist. She
supported me and I got support at work as well. I happened to be in a DBT program at the hospital the psychiatrist worked at, because I was starting to slide, but I wasn't identifying exactly what was going on. When I went in for the intake, I said, "Somebody on staff is abusing me. And he's diverting meds." I thought they were just going to gloss over it. The next time I came in, a bigwig, the Director of Medicine or something, was there. He said, "Tell me. Right now. Tell me what is going on." I told him. He said, "You can choose to do one of two things. You can write him a letter and terminate and we'll take over. Or, you can terminate yourself, in person." So I mulled that over and decided to terminate in person.

I walked into his office and I stood there, proud and tall, and I said, "You have done harm." You know, the Hippocratic oath. And I said, "Dr. So-and-so knows and he knows that you've been taking those medications and diverting them for yourself. And Dr. So-and-so is going to be speaking with you." He blanched and leaned back in his chair and said, "I'm sure he is." I said, "I never want to see you again or talk to you. I am done and I'm outta here." And I walked out. And then the hospital took over. They brought him before the ethical board and he admitted everything. I got interviewed by the Department of Public Health. He had his own attorney and I ended up suing him. It was a nightmare scene. It got settled out of court. It was a nightmare scene. I had to go multiple times to be interviewed by a forensic psychiatrist and it was god-awful, but I survived. Talk about abuse by the system, there we go. It was about as bad as you can get. I ended up going down the tubes myself. I turned into a quote unquote raw mess. I started an intensive outpatient program. I mean, I couldn't even barely drive back and forth. I'd have to stop the car and get off the highway. I was so raw. I keep saying that word, but I was. The intensive outpatient program wouldn't let me talk about what had happened. They didn't want to upset other patients. So, that was that. I couldn't find anybody to help me. I didn't want anybody from around here. I got out of Dodge, as it were, and got linked with the psychiatrist I see now, out of town.

I take great pride in the fact that I spoke out. I've been sexually abused many times. First, I feel compassion, "Oh, I want him to get help." Oh right. And then I changed my mind real fast. It's like, okay, I ain't gonna take this from this jerk. I got raped by my first boyfriend, when I was 14. And, I mean, he's my boyfriend, right. Raped. I've had a history of several raped. Nothing in the family, but rapes, rapes, and more rapes. My mother finally picked up that something was wrong and linked me with a psychiatrist. The psychiatrist was really my only friend. And then my family got uprooted from the state where we'd been living and we went back to the city where I was born. My father had mental health issues too and he was hospitalized and ended up in the state hospital. It was a nightmare. My family fell apart and we left in the middle of the night, my mother, sister, and I. We left the house, my dog, everything I owned, and came back here. We had no place to live, so we stayed with my aunt and uncle. After we moved in with my aunt and uncle, I wasn't in treatment. I was doing pretty darn well.

I began my senior year of high school and I did pretty darn well. I got involved in the civil rights movement. This was in 1964, so it was right before the Civil Rights Act got passed. And, I mean, I was really an activist. But, I was promiscuous. Very, very promiscuous. And I ended up getting raped. But I blamed myself and wouldn't tell anybody. I thought, "It's my fault," because he was my so-called "boyfriend." He was married and I had no clue, no clue. He abused me, frankly. Forced oral sex and all kinds of stuff. He fathered my child, my daughter that I had. We had an apartment with a friend and one night his nephew came to visit. He said he wanted a place to stay. My roommate was away and I liked the nephew, so I said sure. I wake up in the
middle of the night and he's on top of me. So, you know, it's blame, blame, blame towards myself.

When I got pregnant with my daughter, I went to all these different places, first here and then out of state, and then ultimately to a home for unwed mothers. And I realized that they weren't going to let me keep my baby. Nobody was offering supports. So, I threatened suicide. I wasn't going to give my baby up, no way. I don't know if I made it up that I was suicidal or if it was actually true, but my family came and got me of course and they brought me home and then committed me because of the threat. So here I was, in this ancient city hospital. I'm eight months pregnant on a psych unit. This was in the 1960s, so there was this long, dark hallway. There were nuns who were patients there, sitting on the edges of their bed. And here I am, knowing I'm going to lose my child. I wasn't really going to commit suicide. I just said it because I wanted to keep my baby. So they put me in this hellhole. I was hysterical. All I did was cry. It was just god-awful. I don't remember any interaction with the people who worked there. All I did was sit in my room. I mean, I suppose I got food and stuff, but I don't remember that part. I just remember the horror of it. And I do remember, finally, seeing a psychiatrist. I got hysterical with him, sobbing, sobbing, sobbing.

So I said, the hell with this. I am not staying here. I got a Kotex pad and I put a little nick in my arm, somehow, with something, and I put the blood on the pad. I was savvy; I dunno how I even thought of that. And you know what they did? They took me out. They put me on a regular unit, because they thought I was bleeding. Obviously I was okay and eventually they found a foster home kinda thing. They put me in that until I gave birth. I took care of her in the hospital and I held her. They kept you for like four or five days then. Then I had to surrender my little girl. I lost her. I found her later, but that's a whole other story.

After that, I just couldn't function. I ended up just staying home and sitting on the couch. Finally, I got to the point that I wanted to try to work. I worked for a dentist, right out of high school. He wanted to hire me. I was ready to go home from work one day and he comes out from the lab with semen on his pants, and he goes, "Here, this smells wonderful, wanna try?" He smothered me with chloroform to be sexual with me. He was a married man. I mean, this sounds outrageous. This is not a hallucination; this is fact. Fact. And there's a picture on the wall, right in the waiting room, of his wife and his children while he's doing this. I kept say, "I'm dying, I'm dying." I felt like I was dying! Maybe I was, I dunno. To this day, I can't stand that smell. It freaks me right out.

I couldn't do the job, went home and took a bottle of aspirin. Called my mother and said I'd overdosed with aspirin. Called my mother and said I'd overdosed with aspirin. So they put me in the state hospital. I was 19. It was so institutionalized; it was horrific. The beds were so close. People were hallucinating and crying and sobbing all night. We wandered around the day room, you know, the stereotypical wandering around the day room. People could smoke, so there's a little thing on the wall so they could light their cigarettes. There's no place to sit. There are one or two couches that everybody's vying for. I got shock treatments with no freaking anesthesia. There was one person, or perhaps two, that were kind. Everybody else was just horrible.

The next time I received mental health treatment was local. I was in and out of a city hospital. I'll just say it was a nice unit. It was certainly way better. I ended up getting married and things turned around. Everything was great. I was happy. I still didn't have my first child, my daughter, but I had my first son and then my third child. But, my husband turned out to be a severe abuser of alcohol. I had no clue until our honeymoon. The second night, he got flat out drunk with scotch and I cried myself to sleep.
Treatment varied, it varied, but the system was starting to improve. The care that I receive now compared to the care I've received in the past is like day and night. The kindness and letting me have my own input. I'm still on a little bit of medication, but I discuss it with the psychiatrist and she says, “Well, what do you think?” We talk and she let's me give input. Before, I was a frikking over-medicated zombie. I was obese. When I started volunteering at the advocacy organization, I was a zombie. I could barely speak because my mouth was dry, dry, dry. I had no clothes, you know. I had the history behind me and there was a time period where I didn't even talk. I mean, I might have said a little bit, but I was just completely inside myself.
Participant 3: Dinah

I'm 51 now, I was born in 1964. I started receiving treatment when I was, oh God, 17, maybe? I had some depression. I told you I was a birth mother? So, I had my son at 18 in 1982. I went and saw a social worker then and that's what prompted my own interest in social work. I think my interest was in not having an adoption handled the way mine was handled.

I was in private care a little bit sooner than 1998, because I went to a psychiatric nurse for a brief stint. She diagnosed me with ADHD and several other diagnoses. In 1998, when I was 35, I was asked to take a leave of absence from work because I snapped at one of our students, so I went to see a psychiatrist. I'm a voice hearer, so I finally said to somebody, "I hear voices." He immediately said, "Well, how long have you been hearing voices? What is the content?" You know, the typical questions you get. I answered his questions and he sent me away with a prescription for Risperdal.

But, for a long time I believed everyone could hear the voices, which is why I didn't do anything about it. I believed that everybody could hear what I was hearing. I'm still not convinced about that, to be honest with you. You know, what I've learned from the Hearing Voices Movement is that one in 10 people hear voices. And the problem is not hearing the voices, the problem is how you cope with what you experience. So, I think, in part my experience is spiritual and in part it is just my experience. But, it surprises me, I have to say, that other people don't hear the voices. When people said, "No, I don't hear them," you know, I was like, "You gotta be kidding!" But how can you not be surprised, because they're always with me, 24/7.

I'm not in therapy right now because my therapist just left the agency in October or November. It was a shock to me that she was leaving. I would say not just me, but we together as a collaborative, working team didn't have closure because I missed an appointment that would've been the last appointment for her to see me. I haven't pursued what agency she went to and she wasn't at liberty to tell me where she was going. So, yeah, it was difficult. She was the third therapist I've seen at the agency. I saw her for maybe two years and prior to that I saw another therapist for a long time.

I always felt like I needed therapy. I believe in therapy. I believe in talking to someone and trying to figure out what's going on with you. Other people were saying to me, "You need to talk to someone. You need to talk to someone, 'cus you're a sick individual." So, I finally agreed and went to someone. The first therapist I had at the agency was the one I saw for the longest time. I started out seeing her in the mobile crisis unit, so she would come out to my house and we would meet outside in the community and things like that. At Dunkin Donuts or wherever. And then, when I recovered enough to not be in the mobile crisis unit, she transferred me to adult outpatient therapy and saw me there for a long time.

I think the first therapist was just a cool person. I was aware that we shared a sexual orientation and that she was involved with a partner. Prior to the end of us working together as client and therapist, I also learned that she and her partner were married and were having a baby together. So we additionally connected around that. It never entered into our work together, but I felt like she had an understanding of who I am was a woman and that she actually gets it. And she was instrumental in supporting me when I first became involved with the agency I currently work for full time. Before I even started as a volunteer, I started at the agency as a student in
their advocacy education program. I enrolled in the advocacy education program about five years into my formal diagnosis as somebody with a severe mental illness. It was my introduction into the behavioral healthcare community in this state. Before that, I didn't know a behavioral healthcare community existed. So, she was really supportive of me and attended my graduation from coursework. Her whole professional style of interacting with clients was different. While it was clear that it wasn't equal, it felt more equal and felt more human. It felt like she just got me as a person. I never felt like she was a friend, per say, but her role was to be with the patient in the community, so she came to the community and would come to my house. She understood me and was someone who was easy to talk to. She was just different. I don't know what to say. I hope I'm not getting her in trouble or anything like that, but she just kept it real. You know how you just have somebody who keeps it real with you. I dunno, she was just a cool therapist.

And also, I have to say, her whole style and appearance was just different. It was like the friends I have, you know, who dress a certain way and their way of being in the world is different. And there are some people who, like me, have a standoffish attitude towards people. But the way she carried herself made me feel comfortable. She saw me through and worked with me through some of the darkest days. I wouldn't even consider myself as having been "in recovery" at the time she was seeing me. I was paranoid. I had a very low self-esteem because I was coping with the mental health diagnosis. She lived through that time with me and saw me progress to the point where she said, "I cannot keep you as a client anymore. You have to move on from here. You're not in crisis at this point." But she stayed with me and until I reached that point, until I was able to use my community supports, family, and friends. But prior to that, I wasn't able to.

There was a difference in approach in terms of the way the first and second therapist worked with clients and the way they transferred the knowledge that they had and listened. I'm not sure why I left my second therapist. I can't remember. It could have been a combination of reasons; we weren't working well together, or she changed the hours, or I wasn't going regularly, or was not engaged with her, not connecting. She called me psychotic once and I was like, "Okay, then." We had seen each other for a long time, we just weren't connecting. So, I stopped going to therapy for a long time.

And then I started seeing the third therapist. It was originally to talk about weight issues and, you know, why I keep doing the same things that are bad for me in terms of diet, nutrition, exercise, that kind of stuff. I just wanted to talk about the practical stuff that was impacting my self-esteem. Then we were able to delve into some other issues. I'm in a care-giving role in terms of taking care of an elderly parent and I am a lesbian woman involved in a bi-racial relationship. And we were able to connect on a much deeper level. Also, I was going through and completed a master’s program in clinical social work and I haven't been able to find a job as a clinical social worker, even though I work full time at a human rights agency. I work with peers who are in recovery from substance abuse and mental health, so I was doing that kind of work and not really focusing on my social work career, even though I prepared to have a career in social work. So we talked about those issues as well. Then she told me she's leaving and she's going to another agency. That was difficult because she's someone who has some things that, you know, I admire and we made a connection that was much deeper. I was able to connect professionally with the first therapist I began with in the mobile crisis unit and the third therapist I had at the agency, which increased the connection I had with both of them.

I haven't pursued beginning therapy again. I know that there are times in my life when I do wish I had someone to talk to like that. But really, I was probably underutilizing the
outpatient therapy. At this point, I consult my friends if I want to talk about something. It's something that I may pursue, but I spent a long time in therapy already. So, for the moment I just see a psychiatrist for medication management.

I've been at the same agency in this state since 2004. Both my previous therapists and my current psychiatrist were based there. The site is a local mental health or behavioral health care service that reaches a lot of regions. I don't know if I would call them a Local Mental Health Authority, but they are that far reaching and they're funded in part by the Department of Mental Health and Addiction Services. At this point in my life, I would probably look for a therapist outside of the agency mainly because I might be looking for a job within the agency.

I started seeing the first therapist in 2004 or 2005. Prior to that is a time when the mental health care system left a lot to be desired. Individuals in mental health care are kinder now. I've received mental health care in two states. I was hospitalized four times between 1999 and 2004. One of the hospitals actually had an expressive arts therapy program. But, I was also isolated from the unit. I probably left there too soon, because when I realized I could sign myself out, I did and then I tried to go back and they wouldn't let me. But that hospital had art and music; it was probably more humane. I was never restrained, but I couldn't have shoestrings, I couldn't shave, I couldn't do anything like that. So, I'll just be honest about it: I have a higher level of testosterone and grow a beard, because I started shaving the hair on my face instead of waxing it. So, I really had a full-grown beard and the impact that that had on my self-esteem in the hospital can't be underestimated. I usually don't allow the public to see me like that and so other patients, nurses, doctors, everybody saw me with a grown beard. And I wasn't allowed to take care of it without people seeing me.

Shortly after I returned to my job in 1998, I decided to move, which was a mistake, obviously. You know, hindsight is 20-20. So, I moved and ended up in the hospital where I was restrained. But it doesn't matter. I was restrained again in the hospital here after I moved back. From 1999 to 2004, I was living in another state and I received poor, traumatic treatment in a hospital there. The first hospitalization occurred maybe a week after I moved to a different state. I agreed to go and be evaluated because of a situation that occurred between me and a girlfriend. My rights were obliterated. No one told me. I'm really shocked I was even admitted to the hospital in the first place.

I was restrained, not for being harmful or violent, but I think by and large because of the way I looked. I was placed in four point restraints because I went into a patient's room and patted a patient on the head and you weren't supposed to go into patient rooms, but I didn't know what I was doing. But I know I wasn't being violent when I was abused like that. Multiple people placed me on a gurney in four point restraints and I was naked. So, I was really traumatized by the mental health care system. The experience of being in four point restraints was unreal. Prior to that, I really thought of myself as, not like above the law or better than anyone else, but just as a human. It felt like something you wouldn't do to a human. Why would you do that to a human being? It didn't seem like that kind of treatment could be real.

I was forced to take medication, which I later learned you cannot do unless you deem someone to be a danger to themselves or other people. I wasn't a danger. I probably would not have been let out of that facility unless I agreed to take medication. Prior to my agreeing to take medication, the interdisciplinary team would come and try to talk to me about taking it. "Are you gonna take the medication?" "No, I'm not gonna take the medication. Why do I need medication?" That kind of conversation. And I thought, at the time, that I was being reasonable by refusing to take medication. There was no good reason for me to take medication. I was there
for two weeks and this went on for about a week until it dawned on me that they weren't gonna let me out. I was given Haldol when I was restrained and the next day I actually did feel better, calmer. One of my friends came to visit me and I said, "What happened?" Or "Why am I feeling so much calmer?" He said, "You were medicated." And I said, "Oh, is that the impact of medication?" And he said, "Yes." I said, "Maybe I should take it to get out." From going through that experience, I learned that there's a certain way a patient has to talk in order to be heard and in order to get their desires met. I agreed to take the medicine so that they would let me out of that facility. So, the next week I started the medication regimen and was discharged on my birthday a week later. It was February of 1999 when they let me out.

It wasn't like the stuff I learned later about having patient's rights posted and letting them know that they have the right to refuse treatment. I thought I had been committed to the hospital and didn't realize until later that I had signed paperwork, so it was voluntary the whole time. But, I think they were gonna commit me if I hadn't gone voluntarily. It was just a really bad scene. I also had family members that weren't advised of my rights or of their rights as family members. I had family members who would just say, "Take your medicine, take your medicine, take your medicine." It's taking time to create better boundaries with those family members and to heal those relationships. Although I forgave them for their role, because they had a lack of information, I haven't forgotten the experience. So, I feel some kind of way about that kind of treatment. I'm trying to talk about it in a detached way, but I'm getting angry at this point. It's really kinda pathetic.

And then I went and I saw a doctor and I learned quickly that when you go through the many mental status exams, there are certain ways you have to answer the questions and there's certain ways you have to look in order for the providers to view you the way you want. And all the talk was about being med compliant, being treatment compliant, and it really is pathetic, but that's what I went through in order to have freedom. The freedom came with a price.

After I had returned to this state, I was actually restrained a second time in a hospital here. It felt like the more things change, the more they stay the same. The difference between the experiences is that the second time it was two-point restraint versus four. So one side of your body is restrained. I was taken by police from my parents' house and brought to an emergency facility and restrained. God only knows why that happened to me, I still don't understand. At the time I was restrained, my hair was in locks, you know, I might have looked bigger, I weighed more, I'm not saying there's a difference, but I'm saying there's a difference in how you're treated. And I would say I was restrained by at least seven or eight people, most of them were men.

The second time I was restrained, it was again to get me to be compliant with medication that I didn't want to take. I just don't have a "take a pill and you can be fixed" Western worldview. It's never been my worldview. The only reason I took the medication then, continued to take it, and continue to take it now is because I have three family members in particular who believe in Western medication, in pills, and didn't believe that I had a right to choose what kind of treatment I accept. Evidently, they don't believe that the decision to take meds or not take meds is between my service providers, and me because that would be the only reason that they would encourage me to do that. I happen to believe that it's between me and my service providers. So, that's pathetic in and of itself, to me.

Also, the way the behavioral health care system at the hospital was was pathetic because they restrained me. And the only thing I could tell you is thank god I had practice in my undergraduate life with transcendental meditation and yoga, because the only way to deal with
four point or two-point restraint is to go inward, to try to calm yourself. Because what happened is I was confronted with "take your medication" and my blood pressure went through the roof and I'm in these restraints and you can't move and you can't scratch or whatever, you can't do anything. You can only free yourself within and so that's what I did in order to get through the experience until they removed the restraints. Both experiences were pretty traumatizing. When I was a child, I was molested and no one listened to me. I didn't tell about the experience. So, when I was restrained, it felt like my body wasn't my own and no one was available to hear me or that they didn't care how I felt. It felt punitive, not like it was healthcare.

And I'm not saying that I'm perfect, but I'm saying no human being deserves that. That is far from recovery oriented, I think. So, those experiences live with me still. I try to talk to about it in a detached way, until I meet other people who have gone through the experience and I say, "I know what it's like and I know how it makes you feel." And you don't feel like you have the power to do anything, not change the system, not do anything. It makes you feel dehumanized. I went through something and I hope to never go through it again. It is probably what propels me forward, to not have those times return for anybody I know. My experiences in restraints led me to want to be a part of an organization here that works to end restraint and seclusion. I'm angry that that happened to me. I continue to be angry that that happened to me. But, I know that I'm not alone, so I'm angry that it's happened to anybody.

I like to think I'm a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. I think none of us, there's not a single solitary soul, that I feel deserves to be placed in four-point restraint. I wanna know this: how do individual people allow themselves to treat other human beings like that, policy or no policy? I just don't know. I just don't get it. I think it strengthens my resolve to never be a person that makes other people feel that way. I try to look at the bright side of what going through an experience like that does. I've written papers about it too, about the way it traumatizes you. I have to relate to it from a spiritual perspective.

It is the most dehumanizing thing and if we call behavioral health care "care," then where is the care? When it comes to that type of treatment: isolation, restraints, whether they're two point, four point, wrapping people in chains, where is it? I mean, we don't even treat animals like that. The Humane Society exists to stop that kind of treatment, but where is the human Humane Society? When it comes to psych treatment, how do we call it treatment? I mean, one state hospital has increased restraint hours. People have died from restraint. So, the fact that that's our history sucks. I just don't have the words. And we expect people to emerge from that unscathed. I think we do, right? So, whether it's chemical restraints or physical restraints, they're both equally, to me, treatment that sucks. There has to be a better way. And I think we haven't found it yet.

And if it wasn't for the occupational therapist on that unit, I would really have lost faith in humanity. It was the other patients in the unit and the occupational therapist that actually helped me with washing my clothes after I agreed to take their medication to get out of restraints. So, she actually treated me like I was a human being, regardless of her job, you know. It was like she went above and beyond to be kind. Maybe she was someone who didn't like the treatment, the way they treated patients on that unit herself. I can't think of a kind nurse, I can't. The doctor at the hospital, she wanted me to take medicine and so that was her goal, for me to take medicine in order to get out. I mean, she didn't say, "Okay, well, let's look at some alternative ways for you to heal." For her, medication was the answer. And talk about cultural competency and respecting somebody's desires not to take a pill, not to take a chemical! Even members of my family didn't get it and so I knew I would be stuck in that facility if I didn't adhere to their wishes.
I'm angry still. I'm trying to contain myself. My friend says, "You're so calm, you're so calm." I'm like, "On the inside I'm not." But I know looking like me, I have to seem calm. And when I say that I didn't do anything to warrant those restraints, I mean that. Who does anything to warrant that? I mean, I understand restraints are meant to be used when someone is "escalated." I wasn't escalated. People restrained me in order to get me to take medication and because, like I said, I had gone into a patient's room in a distressed moment. I was having an experience, like a dream, where I felt like my brother was talking to me and I went unto the patient's room and I rubbed his head and I called him my brother's name and that was it. Evidently, I didn't have on any clothes at the time. But I wasn't a danger to the patient and I didn't do anything that was violent. They asked me to go back to my room and I was probably still in a malaise or something and didn't want them to tell me to go back to my room. But it didn't warrant eight people throwing me down on a gurney and restraining me for a night. So that was my experience of the pre-recovery oriented system and pre my knowing about my rights. That kind of thing could never happen to me again. I know they say never say never.

I haven't shared that part of my treatment history with anybody except a few select people, so it's not public knowledge. I'm gonna share it with you because you're doing a dissertation on what the system was like and that's how it was for me. We need to work to make sure it doesn't happen to anybody else.

The psychiatrist that I have now listens more. I think he's learned something from, not just me as his patient, but his other patients as well. He's learned to listen more. It could be he's learned something from the Department or from his practice. I feel better about my relationship with my psychiatrist. I feel better going to him. I know that he is extremely busy, because the agency doesn't have many psychiatrists. He also works in private practice. But I feel much more comfortable waiting the amount of time between appointments, like sometimes he'll say two months, sometimes he'll say three months. Right now, we're decreasing my medication, so I see him more regularly and I feel much more listened to, much more heard, even within the time constraint. So, yeah. I wish it were true for everyone. I don't think it's true for everyone. I wish it were true. It's a 20-minute appointment, but he listens to me and he knows that I facilitate a Hearing Voices group for people to talk about the experience of voice hearing and all of that kind of stuff.

I'm involved with the Hearing Voices Network and we brought this to the state through someone who worked for the Department of Mental Health and Addiction Services. We started out with six groups and now we have 14 groups. So, we have a voice and I have a voice today that I didn't feel was being heard by service providers before. I still think there's some service providers who don't hear me when I speak, who don't recognize that we do have choices. As people with a mental health condition we have a choice. Ultimately the choice should lie within us. The choice should be between me and my service provider, not other people who think they know what's best for me. I have an attitude and some anger about it, I know you could probably hear that.

The psychiatrist said that he has patients with tardive dyskinesia so bad that he can't continue to prescribe anti-psychotic medications to them. He checks me to make sure I don't develop it. And so he's working with me in reducing the anti-psychotic medications. I hate myself every time I take meds. While I never desired to be on any psych meds in the first place, I've taken a lot of them from 1999 to the present. Some of them I've had adverse side effects from. I initially took medication to get out of the facilities and then to satisfy my family, who, like I said, believed that you should take medicine if you have a mental illness. My family
has had the biggest influence on my using medication. They would have conversations with the doctor. But it's also been my own doing and I take full responsibility for continuing to take the medication even though I feel some kind of way about it and don't think it's effective. It has never stopped the voices that I hear. And so, like I said, the medication only helped calm me. I think it focuses me, that's the impact that I feel. But I take a medication that other people wouldn't be caught dead taking. I used to take the maximum dose of it. I don't take the maximum dose anymore and sometimes I wonder if I should and sometimes I quite frankly wonder if I'm addicted to it and that's the reason I won't stop it completely. 'Cus why take something if you don't believe it works at all? I mean, it never worked.

I used to take anxiety medication because I experienced anxiety and social phobia. I couldn't be in public, period. I couldn't go to grocery stores; I couldn't do events. Prior to that, I was teaching in front of groups of people, that's my role now in the job. But I couldn't be in public places, I couldn't facilitate support groups where there were people talking because of my experiences with the voices and how they make me cringe sometimes and feel out of sorts. I couldn't do it. But I've recovered and now I can do it. Really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years and, you know, I've done other things I don't like. Like I said, I'm not perfect.

But, I feel like my psychiatrist, at least, is getting it and he understands. He's not certain what the outcome will be with me, but at least he's willing to work with me and say, "Okay." I've seen this psychiatrist since 2006, maybe 2005 or something, he's been my psychiatrist for all this time. And so he's seen my growth and development as a human being and as a professional and I think that has probably made a difference for him. You can't be in behavioral health in this state without knowing that recovery is possible, I don't think. Is it possible to not know that? It's real for people. There's some alternatives that we need. We need to be about integrative medicine, holistic healing, and offering people choice. People want to be offered choices and be a part of their treatment plans. I still take a little medication, but it is possible to use programs like a WRAP as well as holistic healing and manage our symptoms without medication. I believe. This is just me. But if another person believes that they need a little medication and they need those other things, then a therapist should support them in continuing to do that.

So, I think we have a long way to go in terms of helping people. Even with the third therapist I had, an old treatment plan was still being used, just to get you to sign it so that they could get funding. Probably is was partly due to my lack of insistence that I be a part of the treatment planning. I think that still is an area that needs to be addressed. We have a document that Yale is responsible for putting together, called Getting in the Driver's Seat of Your Treatment Plan. That document is still not being utilized everywhere. So we have a long way to go in terms of helping, I'm going to call them patients, but helping people get in the driver's seat of their treatment plan with agencies. Even me, knowing and teaching it, I still go to a facility and on the most recent treatment plan I signed, I really just signed it. We didn't have a conversation first about what my goals are, although she knew that I want to get a job as a social worker, that's not in there. If we don't, as clients, insist that we're a part of it and that the conversation takes place, I think there's a risk that it will continue at the status quo. It's almost like we have to insist on saying, "Are you gonna ask me?" And we can do it nicely, we don't have to be hostile like I am. We could do it like, "Are you gonna ask me what my goals are in different areas of my life? Do I have financial goals? Do I wanna own a house or get a different
apartment? Do I want to have social relationships that are rewarding?" You know? "Are you gonna ask me those questions?" And I think we have to insist, as clients. We have to give them the questions when they don't have them.

But, I also think some training has to take place on the part of agencies' staff development. Like, they should know that that document exists. Especially the staff coming out of social work programs, they should know about those documents and other documents like that. They should know about WRAP, because a lot of people in this state who are clients have a WRAP and if the clinicians don't know that there's such a thing, it can't be put to use. I mean, I don't know who doesn't know, but I'm sure there are some that don't know. Do you know what the WRAP is? It stands for Wellness Recovery Action Plan and Mary Ellen Copeland developed it and the Health and Human Services Department uses it. You know it's called recovery planning or planning recovery, recovery action planning, or something. It's been translated across the globe and people use that to help them manage their symptoms and to take action when they need to address certain areas.

And that's the kind of education people should be getting. Well, I've found myself in a position as a client, sharing information with my therapists that they don't know. And not only that, as a spouse of a woman who is in private practice, sharing information with her that she then shares with her therapist that they don't know. I find myself in that role all the time and I'm like, "Why don't they pay me?" It's so funny. But there's pockets in which people need training and they need professional development. They need advanced learning in those areas and sometimes it's unfortunate when the schools don't prepare them. Like, I went to this agency as an intern and the director of the agency said that the school that I went to is still using the same curriculum from 20 years ago. And, you know, I found it rigorous and it was kind of an insult to hear her say that and I was like, "Wait a minute," 'cus I learned a lot in that program, you know, and the teachers weren't outdated at all. But, it's still the same thing about what they want professionals coming out of master's social work programs to know and be able to do. But really, the benefit of sharing information is that my therapists treat me better as a result and I also learn from them, 'cus I don't know everything. Like, that's why when the third therapist left, I experienced that loss greatly, because, you know, I was learning a lot from her as well.

I think my therapists view me as capable and competent, but they didn't always. Like I said, the second therapist I saw, she called me psychotic. And I thought, "Why would you call someone that label?" You know, I mean, I can't remember the whole context to give you an idea, but I just think that's a travesty. I can't figure out what happened, I can't make excuses for her. We were having a conversation and she was like, "Yeah, but you're psychotic." And she was trying to talk to me about something, you know, maybe it was a conversation about medication again. For them, it's always been about "Are you taking your meds?" That wasn't her role, her role was to do talk therapy. It's using a stigmatizing word. I can't think there's ever a reason to be engaged with a client, having a conversation, when I would call them a label that is in their file. I wouldn't. For what reason? Can you? I would refer to clients the way that they wanted to be referred. In fact, I was in a conversation with one of my friend's parents and I said, "'What is your first name?' And she said what her first name is. And I said, "What would you like me to call you? By your first name, by a Christian reference, prefix, or by your last name?" And she said, “Whatever you feel comfortable with." Well, she's my friend's mother, so, you know, I don't know. I have to decide what I feel comfortable with. But I wanna demonstrate respect and so I think that the difference in the system is that, for some reason, there are some people still who don't believe they should respect clients. And that's a problem. I think.
But that is disrespectful, I think, to call someone psychotic when that's not a word I use to refer to myself under any circumstance. So, I mean, more power to the people who do, but I just don't want to call myself any label. Other than my name. And I know that service providers are human too, right. They have good days; they have bad days. Perhaps I'm giving you an assessment of the second therapist I had on her bad day. You know, I don't know if it was a bad day for her. Of the three therapists I had at that agency, I do know that she was the least willing to talk about herself or answer questions that I had about her personally. I know I probably shared some stuff with her that was hard to hear, but I think she disrespected me in that instant, even if it was a bad day. She disrespected me and I carry that. I've shared that story with other people and they're like, "What, she called you what?" I said, "I know!"

I couldn't defend myself, 'cus one of the things that I don't do very well is self-advocate. I teach it to other people. You know, it's one thing to teach it, it's another thing to practice it. But, that's the kind of advocacy we teach: self-systems and legislative. You have to speak up for yourself, I know, but there's something that prevents me from speaking up and it's probably because stuff like that hurts me deeply, like being called a name, hurts me so deep, like to my core, that I don't always have the words to combat it. And also, it's because I know it's either going to hurt me deeply to my core and I'm sensitive, or I'll get angry about it and I don't want to explode, because the cost of me exploding is much greater. Just because I'm a black woman, it's greater. It's greater for black men; it's greater for black women. It happened to me at the Department of Motor Vehicle. The woman was talking to me in a way that I felt you shouldn't talk to human beings. And I didn't say anything, 'cus I said to myself there's a lot of people, a lot of witnesses, they won't witness her talking to me in a disrespectful way, they'll witness my response. And so my response was to walk out, because I don't want to make a scene, because I will end up one of two places: jail, and I don't want to end up there, I never been there, or a psych ward. And so it can't happen. The way I would get treated by law enforcement officers is much greater cost to me. I learned my lesson and that's the lesson, unfortunately. The lesson I learned is that the thing you think won't happen to a human being, will most definitely happen to me. So, that's the stuff that will make you cry if you allow yourself. Absolutely. Those are terrible lessons to learn. It is a terrible lesson to learn, but I learned it well.
Participant 4: Dolores

I'm now 64 years old. I was probably 19 years old when I first entered care. I was a biology major in college and graduated with a Bachelor of Science degree in biology. I was first in private care, then I was in a hospital. I was at that hospital a couple of times. And now I'm at the clinic. But before then I had been in private care. Now, I have a therapist as well as a psychiatrist who I only see every couple of months for medication. I was in group therapy also at a hospital, but after I lost my mother in July I started a grief support group through a community center instead.

I was sexually abused by my grandfather, so I suffer from posttraumatic stress in addition to major depression and anxiety. For the past 10 years, maybe less than that, I've been the primary caregiver for my mother, who had dementia and a lot of physical problems. I also, in the course of that, became estranged from my sister and brother. So, that was an ongoing problem for me and a great stress.

I have a great fear of people that I feel goes back to my trauma and it wasn't only that trauma, with my grandfather, but I think that was the biggest one. So, I have a fear of people and where others would gravitate to people and want to seek them out and talk to them, I can't always do that, especially if I feel in a really depressed way. I can just isolate myself and not reach out to people. Of course that's my upbringing too. My father was a big one for not telling people your bad things and just being upbeat and good. And to an extent I have incorporated his need for humor, because I do use humor a lot of times in ways that are kind of the opposite of what I'm feeling. So, I'll seek out a TV program that's funny and use humor to kind of help me out.

My first attempts to find care were kind of hit or miss, because my parents were not behind me getting involved in therapy. They're from a different generation altogether and they didn't want people knowing that I was going to be in care.

A professor of mine told me about a woman who people sometimes spoke too when they weren't living up to their intellectual potential or when they were having psychological problems. He wanted me to see her and so I contacted her. At that point, I was working in advertising. She gave me the name of this person to go see, but it was weird and he couldn't see me regularly and was more interested in giving me meds. Then he wanted to do this hypnosis thing and so I said, "Well, alright, I'll try it." Really, it was just about touching your emotions more deeply. I was pretty much aware of what was going on, so, I mean, there was no way that he could have taken advantage or anything like that.

Then at one point, we had talked about me going to a live-in place, but when I spoke to the people there they said, "But you're working and really you should continue with that if you possibly can and just do outside therapy." So, that's when I got involved with my psychiatrist slash psychoanalyst. Looking back on it, I think that working with him triggered my posttraumatic stress, because the psychiatrist was an older man and my grandfather had been an older man. He also had a walk down type of office and he had couch-type thing. He didn't have me on the couch; he had me sitting up. But I just started getting worse and hearing voices and I started hallucinating things and I was in and out of hospitals. So, I wasn't doing well at all. His type of therapy, where you don't even say hello to the person, that was not for me at all. It was just so impersonal. And then he really wouldn't talk that much at all and sometimes I couldn't talk and I would just be looking at the floor and there would be silence for almost 50 minutes and so that was not really conducive to me speaking or feeling comfortable or anything like that.
I had been with this artist for a year and I was in love with him. He was an older man though and he had gotten into debts and decided he needed to go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided that's where he was gonna go, but that just really hit me badly and that's when I ended up in the hospital. When I tried to say to the doctor, "I think there's something here and I'm not dealing well with his leaving" and all that, he just said, "Well, there's nothing to do with that."

And at that point he had said I was paranoid schizophrenic and so then he was pushing all these heavy-duty so called tranquilizers and I kept telling him, "They're having a paradoxical effect on me." I didn't know about paradoxical effects at that point, but I do at this point. So, I'd say to him, "I'm feeling worse and I'm feeling more anxious and more paranoid" and all this and he'd say, "No, no, no. You can't possibly, because these are supposed to treat that." My parents and my father especially were very mad about me continuing to see the doctor. I was just so sick and then I felt like, well, if I give up on this then I am just kinda wimping out and maybe I need to hear what he's saying or need to do this, but finally we ended, because we kinda got into this tiff with each other and I had already started to ask about another therapist. So, we did end and that was probably the best thing anyways.

After I saw the psychiatrist who did psychoanalysis, I worked with a different psychologist. I found I liked that interaction better. He was a friendly person and he would actually say "hello" and so there was interaction and he would talk to me and it wasn't just me spouting off for 50 minutes and maybe getting an "mm" or an "ern" or something like that. I like to have dialogue and have someone give me feedback about what I'm saying.

My psychologist and psychiatrist started to feel at some point that I should get into Dialectical Behavior Therapy. The first experience I had with it didn't feel really helpful to most of us in the group, because they weren't showing us how it could relate to our own life and how we could use it every day. So, I don't think I got so much out of that one. But then I was outpatient at a hospital and I went to their Dialectical Behavior Therapy and I was in that for about a year. In that one she really tried to give us examples of how to pertain it to our lives and she'd give us handouts of different meditative styles and things likes that. She also told us about art therapy and things like that that could help also.

When I was at the hospital doing the DBT group, I said to the woman running it, who unfortunately was in charge of my therapy at the hospital, "I really think that I need to be in a trauma program. I've really never dealt with that whole area of my life." At first she was telling me, "Well, no, no. I don't think your insurance is going to cover it. And oh no." And I said, "Well, then can you find out if I can pay monthly so much, or whatever, 'cus I really think I should be doing that." And then, I guess she realized I was serious about this and so she went to talk to the director. And he said, "Well, I'm not going to keep anybody out of a program just because their insurance won't pay." But, she made it so I could only stay for eight weeks or something like that. And at the end of that, even the staff said to me, "Well, we were surprised at your leaving." And I said, "Well, it isn't my choice. She's saying I have to leave." And so it's too bad they didn't kind of try to say, "Well, look, she really needs to stay in this." 'Cus there seemed to be some kind of, unfortunately, battle there of who was gonna be in charge of the care or whatever. So that was an unfortunate thing, 'cus I didn't feel like I could stand up and say, "Look, I really need to continue on with this. And so we need to figure a way out."

At the same time, I had started a grant with some other people to research different trauma programs. I wanted to put one together, 'cus at that time I was still in the Clubhouse. I felt that they really needed a trauma group. I ended up being the leader of the trauma research group,
which I didn't intend initially. And at one point, I was giving one of the members a ride home, and he disclosed to me that he not only was a trauma victim, but he also molested young kids. And that just really freaked me out and got me triggered, because my own thing was of being a young child and being molested. So, I went to the head of the rehab area that I was in there and they were trying to convince me that I shouldn't say anything to anybody, because that might upset this guy and that I should keep this under wraps. And I said, "But that isn't fair to me." So finally, in one of our group meetings, I just said "I'm sorry, but I'm not going to be able to not say this to everyone in this group and, you know, I'm sorry if this upsets this particular person, but I'm upset and I'm triggered and I need someone to help me with this and maybe some of the other people do also." So, we then had a woman that worked in their emergency services and she actually was a trauma specialist, so she came into some of our groups. And then I actually became one of her patients or clients after that.

The hospital finally put together a trauma group there, even though they kept fighting us about that. I said, "I think you need to address the trauma part of it or you're still gonna keep having people with recidivism and all that." So, I finally went to their trauma program. At one point in my life, I had started cutting and I just couldn't seem to stop myself. I didn't realize it was related to the trauma until I went into the hospital's trauma group. I was using razor blades and then I was using a scalpel, but my father found that out and he took that away. But it seemed I couldn't stop doing it and I just hated myself and I would burn myself. Well, at one point I used our electric carving knife on myself. I just really hated myself and at that point in my life I was blaming myself for the whole sexual thing and I thought I must have done something to get my grandfather to do that. Of course, in the trauma group, I learned that wasn't the case. But it wasn't until I started taking care of my nephew before he went to kindergarten that I stopped cutting. My sister had him with her first husband, who she's divorced from, and she was going back to work and at that point I wasn't working so she asked me if I'd want to take care of him and I said, "Alright." I just felt really close to him and he felt close to me and it was love I needed. But at one point during the trauma group I needed to call my therapist who was very knowledgeable about trauma and I said to her, "It's been years and I haven't felt like cutting, but I feel like it now." And so she said, "Well, I think it's the trauma work," and she said, "if you really think you can't stop yourself, then you need to go to the hospital, but if you think maybe you can, do some journaling or something like that to get yourself away from feeling like that." So, luckily, I was able to not do any cutting and so that, hopefully, is the end of that. But, I guess you always have that fear of not knowing what will happen.

I've been going to the same clinic for therapy for almost 10 years, I guess. I've had to change therapists a few times, when they leave to do another job or whatever. So, I have had a few that have been very good and unfortunately they've moved on. I've been with my current therapist for at least two or three years. Some therapists keep a dialogue and will kind of talk to you, "Well, okay, you said that, so I see how that related to that," but I haven't had all that many who have been that astute or whatever you want to call it. And as far as doing the trauma part of it, I feel like that's still something that needs to be addressed and I don't feel like I'm with a therapist that I would do it with.

I ended up seeing him 'cus I was in the intensive outpatient there and I had been seeing this woman who I liked, but she told me that she was taking on a different job there, so she wouldn't be able to see me every week. And I felt that because of my whole situation, my mother and everything, that I needed to see someone every week. So that's why I ended up switching to
this other therapist. And for a while it seemed to work. But now I'm going through a weird situation with him, where he's saying or doing things that are just making me more anxious.

For instance, I've been having this problem with Department of Motor Vehicles, 'cus unfortunately my insurance company made a mistake and transferred funds I had already paid to this new, lower fee insurance that we're going to start in October. But you don't take the insurance away from a person or make it look like I didn't have any insurance. So, DMV sends me this letter that I'm not gonna be able to register my car because I didn't have insurance from June until October. Things like that just get me very anxious and I'm never sure that I'm gonna be capable of taking care of them and handling them.

I wasn't able to get on the website myself and we have a resident advisor who's really very nice and everything and for some reason we couldn't get on together either. But she decided to call the insurance company and see if she could get somewhere better with them, 'cus I thought I had solved the problem and everything talking to someone at the insurance company and apparently that may not have been the case, 'cus then she talked to someone and they actually send us an email exactly what they were gonna send to DMV and the person I talked to hadn't done that. And I said to her, "Well, how come you could get somewhere when I couldn't? I don't understand it." I mean, I was very kind and everything and considerate and she said, "Well, sometimes when it's not your problem, you know, you're able to do it better for the other person." But I'm just thinking that maybe they see that another person knows what's going on. It's kinda like having a witness. Of course, I have trust issues so that's why I kind of get all upset and wonder if this is gonna be taken care of or not and all that.

So, what my therapist did was, he gets on the website and he goes, "Alright, give me your license and I'll put in your date of birth and your everything." So, he gets onto the website, but what it says is that I owe this penalty of 200 dollars. And I said, "What! Well, we just sent the proper things, so maybe the other person didn't send it or the DMV is so behind." But he says to me, "Well, I think you should go down there in person." And I said, "How do you think I'm going to stand there for two hours? I can hardly stand." I have a lot of arthritis pain. So, I said, "I can't stand for 15 minutes, so I'm not gonna be able to stand for two hours or more. Well, see now you've gotten me all upset about something that I felt okay about." So, he laughs and he thinks it's funny. And, lately, he's done that. He thinks things are funny when I don't think they're funny. But anyway, the resident adviser said, "No, just wait and let's see, you know, if it gets taken care of and all that."

I dunno what's going on with this therapist, unless it's just that I'm more depressed and I'm not finding levity in anything. But some of the things that he's finding funny, I'm just not finding funny. I guess he's maybe just nervously laughing about something. Maybe he's just really in a Christmas mood this year and I'm not.

At one point, I was trying to do this thank you card design for this woman. We had started before my mother died, so it was like maybe May or June that she asked me about doing it and so I had a design that I was gonna use and everything, but she wanted me to bill her before the end of June so that it would be that fiscal year. But then I got behind on the card and so, for instance, the therapist was making fun of me about that, instead of understanding that my mother had died. Even though I had her in hospice at that point, I didn't expect her to die at that particular moment and day. 'Cus that weekend, which was July 4th, she had been pretty well and still knew me and all that, so I hadn't expected her to do. So the therapist was like, "What do you mean? You got paid for it and now you're not doing it." And I said, "Well, if I can't do it you can be sure I'll give her her money back. But, I said, "She wanted to be billed and in fact I've spoken with her
and she's been very kind and very understanding and she said, 'You just take care of yourself. And promise me you will take care of yourself. And whenever you can get the card done, then you get the card done.' And you can see that this is not helping me. It's really not helping me when I leave there and then I feel worse about not having gotten it done sooner.

Most of my experiences with the Clubhouse were good. For a while, I really felt connected and seemed to be liked by a lot of people at the Clubhouse. And in fact I became like a volunteer leader. I think I left because I was going back to school. It just wasn't really meeting my needs anymore. I don't like to put people in categories, but it seemed that is more for less highly functioning people. Kind of a place they could go and be.

I think the Clubhouse was helpful to me and I think clubhouses are helpful. But, it seems that now they're starting to get away from the old clubhouse model or whatever and I think there still is a need for that. Now it's more groups and not so much that they'll help you to go out to some nice things. Like, we used to do a lot of different things that I probably wouldn't have gotten to do and at that time you only had to pay five dollars and what they did was they kind of put that into a pool of money and so they would pay the rest, like if we went to a movie or something like that. So they made it very affordable and they don't do that now. It's one major outing that they do and they don't to the weekends like we used to do. Because a lot of people, I think, on the weekends can feel like at a loss and "What do I do?"

It's too bad they don't have some kind of a graduation group. But I guess they expect that you'll get together with those friends or whatever and do your own things. But it might be a nice thing to have somebody that was a staff too, in case you wanted to bounce certain things off of them and stuff. I live in subsidized housing. It's mostly for elderly, but there are a few of us that are younger and disabled or whatever. And the resident advisor is a very kind person and so I feel less alone because I can go to her about different things that come up, financially or just housekeeping type things or whatever.

Unfortunately, I haven't had such a good experience as far as trying to go back to work and I feel that I wasn't dealt a fair option in that area. The vocational services staff person I worked with would go into the interviews she set up for me and would tell them that I had a mental health background before they even met me. At one point, I had gotten to the place where we were going to interview and she wasn't there. I kind of panicked and said, "What do I do now?" And then it got to be late and it was almost time for the interview, so I figured I better just go in and then she all of the sudden flips in with her car and makes a turnaround and goes back out and I'm thinking, "What's going on?" And then she gets there and I said, "Well, what happened to you? I don't understand." And she goes, "Well, if you were so concerned, why didn't you make the call yourself? You could make the call to the company yourself." And I said, "Well then what do I need you for then?"

So, that got me upset, 'cus we're getting into a little tiff before we even get into the interview place. And then we go into the interview and I guess the interviewer didn't know that I was going to be there with the staff member. So she kind of looked at me like, "What're you doing here?" And so that got me even more within myself and I thought, "Oh, gosh." So she took the vocational person in and talked with her and then she came out and she was warmer and offered her hand to me and said, "Well, come on in." And most times, when the people did meet me, they seemed to find something they could say was good about my artwork or this or that. But they all wanted me to know the computer, which I had never gotten into. I said, "Well, could I do an internship?" And they said, "Well, no, because we've had people in the past and it hasn't
worked out." I found that they were looking down at a person with a mental illness and not giving me a fair try at things.

One of the vocational support people was putting up all these stumbling blocks in front of me. And it wasn't just my opinion of what was going on, but it was other people that then saw what was going on. They were helping me to go back to school for the computer and for graphic arts and multi-media. So I have an Associates of Science from community college. But, for some reason, she would send me to the financial aid people with the wrong information and the wrong dates and all sorts of things like that. And they'd say to me, "Now she knows what to do, I don't understand what she's pulling here." The guy at financial aid said, "Well, I have to wipe this out and I have to put this down as the date, otherwise you're gonna be going back and forth here with this paper for no reason." And I said, "Well, you better initial it or something."

I would have the person who was supporting me through my education sit in on my meetings with my vocational support person. And so when we get into the meeting with the vocational support staff, she's like looking all the sudden at me and with this smile and she says, "Well, now you're an artist, so what's to stop you from whiting this out and writing something different in there?" And the educational support staff said to her, "Why on earth would you say that to her? That doesn't apply at all." And she goes, "She's never done anything that's been underhanded or not decent or honest." So, after having humiliating experiences with her, I finally did switch with the help of an advocate who came in and we talked with her boss and I just switched to somebody else.

But then, I came across this woman that was supposed to help me with updating my resume. I don't know what was going on with her. It was obvious there were a lot of people, 'cus they would talk about it and think it was real funny, who had been incarcerated and in jail. And maybe those were the only people she was supposed to be helping with their resumes. She'd come out late for our appointment, she'd call me in and then she'd say, "Well, you know, we only have so much time." And I said, "But I was here on time." And she goes, "Well, we only have five more minutes," and she said, "I really don't have time for this." And I thought, "Well who do you have time for then?"

But I didn't say too much because you feel like they're in the power and they can do what they want if they so desire. I feel like, well I don't want to end up in the hospital, so I better not say anything about this or that.

Here's an example of where I never should have said anything, because it got blown out of proportion. My father had already died. I was going through school and my mother was really going down hill. She was still at the house, 'cus I was able to keep her there, but she was very angry, very negative with me, like I was dirt under her shoes, even though I was, as I was told by everyone else who saw the situation, keeping her able to be at home still. And I didn't realize how badly she was going downhill emotionally and mentally. So at one point I must have said something to someone like, "Well, I feel like harming myself or I feel like sometimes my mother is just so nasty and horrible to me and I could just give her a little push or something." But I never, ever had or ever would have, but unfortunately I said that to someone and so then they felt like they should bring in Senior Protective Services. I don't even like saying this, I'm sorry. I wish I hadn't said it. But, let's just put this to rest, this man found I hadn't ever hurt my mother and I never, ever would hurt my mother. And in fact my mother was the one that slapped me and used to, with my brother and I, whack us on the legs and stuff with a stick.

Then I asked my brother for some help, 'cus he was out of state and so was my sister. And I was still trying to keep my mother at home. We had homemakers there and companions...
and stuff, but at one point, the person had left and I hadn't gotten home yet, and my mother dragged a chair and was going to try to get up on the chair and fix something on a curtain. I get home and her leg is all bleeding and everything, 'cus she had thin skin and all. So I finally said to my brother, "What are we gonna do? Her judgment is off. Are we gonna wait until she breaks a hip or something worse?" So then he was all annoyed with me and how dare I ask him for help. So next time I tried to say to the agency, "Well, I need to take my mother to get her hair done" or "I need to take my mother to a doctor's appointment" or something, then I had my brother or my sister-in-law call me up. Well, not my sister-in-law, she wouldn't, but she had my brother calling and saying, "Well, where do you think you're taking her?" And I said, "What do you mean?" And he goes, "Well, you have to get my okay or my wife's before you take Mom anywhere. And it should really only be to take her to a doctor's appointment or to get her hair done. And finally after him doing that kind of stuff and then having people watching me or not watching me and what I was doing or not doing, I finally said to the people at that agency, "You tell her son to call his mother and tell her that she has to get his permission or her daughter-in-law's to go out with me for whatever it is." It just became horrible.

Medication has not worked well for me, even now. When I was in the intensive outpatient, they brought in a new psychiatrist who was supposed to be for the particular group I was in, but he wasn't my regular psychiatrist. There was a certain medication that I was using and he was against me having it and using it. He said, "Well, no, no, no. You're going to be going off of this." And I said, "You will give me no quality of life, then," I said, "and I don't think that that is fair." But he was sticking to his guns and he wasn't going to give me the refill and then I guess the pharmacy said, "Well, this is not a medication you should take her off of, you know, just like that." So he said to me, "But I thought we agreed." And I said, "But I didn't agree to go off of it like that, completely. And you said we could try going down on it and I agreed to that but I didn't agree to not at all." So, I got pretty upset, crying and stuff, to my regular psychiatrist and he said, "Well, do you want me to speak to him?" And I said, "Well, I don't know that that's a good idea." So, finally, this new psychiatrist said, "Okay, I'm gonna allow you to stay on that medication." And he said, "Because you said to me that it would affect your quality of life and so you can stay on that." But, that put me through some trauma for a while.

The medication I'm talking about, Lorazepam or Ativan, seems to put me in a less depressed mood and to make me want to live. Now my regular psychiatrist is telling me that I really should get off of that medication, that it's been linked with Alzheimer's and that type of thing. But since my mother died I'm really not in a good place at this point. So, I had tried not using it and just using it sparingly and all that. But this past time I saw him I said I would sign something releasing him from any responsibility of anything, I said, but I don't think I can completely do without this or having it available if I did need it or whatever. And so he said, "Well, you don't have to sign anything, I'll just put it in your chart."

I feel like psychiatrists sometimes don't think before they talk. I don't know what it is with them. Well, now they don't see you that often anyways, so they don't know a lot, but my psychiatrist seems to take more of an interest in what's going on than in just prescribing the pills. But, recently I was talking to my psychiatrist about going on a different anti-depressant and he's saying to me, "Well, you could feel nauseous for at least two weeks or more." And U said, "Two weeks?" And he goes, "Well, say you have twenty years to live. Two weeks out of twenty years is not a big thing." And I just kinda looked and him and he gives this little grin, which is weird because he doesn't usually smiley, and he goes, "And besides, most of people can stand losing
weight," he said. And I just kind of was like, "Yeah, if you had to take these psychiatric drugs, I
don't think you would necessarily stay thin, 'cus they do increase your appetite and everything."
So, I just thought, well that wasn't very kind.
Appendix G: Meaning Unit Transformation Tables

Participant 1: Thomas

<table>
<thead>
<tr>
<th>Themes</th>
<th>Meaning Units</th>
<th>Transformation 1</th>
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<tbody>
<tr>
<td>I have a, ah um, a PRN psychiatric nurse that prescribes my med--medication, psychiatric medication.</td>
<td>Now, I see a psychiatric nurse who prescribes my psychiatric medication.</td>
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<tr>
<td>Belonging and Responsibility</td>
<td>And, um, I'm a member of a clubhouse? And I am the, uh, chef of that clubhouse. So I help run the culinary unit. And, uh, they--they--they're based on the recovery model based on Fountain House. [I have been involved with the clubhouse] Um, officially since ‘98, but before that maybe ‘95, 1995.</td>
<td>Since 1995, I've been a member of a clubhouse that's based on the recovery model of Fountain House. I'm a chef at the clubhouse and I help run the culinary unit.</td>
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<tr>
<td>[I have worked with the psychiatric nurse for] Oh, gosh. Quite a while. Um, I--I would say probably 15 years or so. Well, the, uh, the--the medication review lasts about 15 minutes. And when she--that--they--she goes over my, um, symptoms and how I'm--how I'm doing and sometimes I talk to her about a problem that I'm having. But, the, uh, it usually is limited to 15 minutes and then she'll say, &quot;Well, okay, we'll continue with the, uh, medi--medications the same, don't make any changes.&quot;</td>
<td>I've worked with the psychiatric nurse for 15 years or so. When we meet, she goes over my symptoms and how I'm doing. Sometimes I talk to her about a problem that I'm having. But it's usually limited to 15 minutes and then she'll say, &quot;Well, okay, we'll continue with the medications, don't make any changes.&quot;</td>
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<tr>
<td>Work-Readiness rather than Emotional Support</td>
<td>I have a supervisor [at the Clubhouse]. And I also--the director, sometimes I talk to--to the director. Usually, it has to do with work. But, if-if I do have some kind of problem, sometimes I will talk to my supervisor. Yes, but I think the emphasis of the clubhouse is on work readiness, so it's not so much, um, discussing--they don't really have time to discuss, um, my personal problems.</td>
<td>Usually, when I talk to the director of the clubhouse, it has to do with work. I have a supervisor, and sometimes I will talk to her if I have some kind of problem. But, the emphasis of the clubhouse is on work readiness, so they don't really have time to discuss my personal problems.</td>
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<tr>
<td>Changes in Support</td>
<td>So, if I had to do that, um, I used to have a therapist, and sometimes I talked to the therapist, but, uh, right now, um, there isn't really anybody that I could talk to in--in depth about any kind of problem that I'm having. In terms--personal problem, if it was a work related problem, then I'd be able to talk to them. [I stopped seeing the therapist] Um, probably about 15 years ago also. [Pause] Um, for the most part I [pause] I am okay with it.</td>
<td>I used to have a therapist, but now there isn't really anybody I could talk to in depth about personal problems. I stopped seeing the therapist about 15 years ago. For the most part, I'm okay with it.</td>
</tr>
<tr>
<td>Planning for the Future</td>
<td>Well, right now I'm trying to, um, set up, um, trying to understand my, uh, plans for, uh, es--estate planning. My parents are aging. And, I'm trying to, uh, come up with a plan that will allow me to, uh, keep my entitlements and, uh, keep my, um, in--inheritance or anything else that comes along. I'd like to live where I'm living now and so I--uh--I would talk about that with</td>
<td>I'm currently living with my parents, who are aging. I'm trying to come up with a plan that will allow me to keep my entitlements and inheritance. I'd like to continue living in the same home when they pass away. In the past, I might have talked to a therapist about something like this. Now, I think I'll probably talk to a lawyer.</td>
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them, instead what I think I'll probably do is talk to a lawyer. [I am currently living] With my parents.

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<tr>
<th>Changes in Support</th>
<th>I do have also, I forgot to mention, I have--I used to have what they call a case manager. Now, they have something called community support program. So, um, they don't really have case managers the same way they did before, but sometimes if I have as--uh--uh--important question I can contact that person.</th>
<th>I also used to have a case manager, but now they have something called a community support program instead. In the past, if I had an important question, I would call my case manager.</th>
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<tr>
<td>Support in the Past</td>
<td>Um, well, when it was case management, uh, what they would do--what--uh--this person did is [sic] set me up with my entitlements. And refer me--make rec--recommendations about different people that I could meet--need to see, like, uh, sh--she, uh, set me up with a dentist, a good dentist that takes Medicaid. Um, so sh-she helps me with, um, getting connected with services.</td>
<td>The case manager I had in the past set me up with my entitlements and would make recommendations for services, like a good dentist that took Medicaid.</td>
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<tr>
<td>Self Sufficiency vs. Needing Support</td>
<td>That's how it was in the past. Um, I could try contacting the same person again or I might be, um, referred to a--an agency to contact [pause] to, uh, ask directly. Uh, ask the question directly to them.</td>
<td>That's how it was in the past. Now, I could try contacting the same person again or I might try to directly contact an agency.</td>
</tr>
<tr>
<td>Self Sufficiency vs. Needing Support</td>
<td>Um, [pause] I think that I don't--I don't need as much contact with them as--as I did in the past. Um, so it--it--so it feels--s--sort of--it feels good in a way to be self-sufficient, um, but at the</td>
<td>I think that I don't need as much outside support as I did in the past. It feels sort of good, in a way, to be self-sufficient. But at the same time, I think that once in a while I might run into a</td>
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<td>Self Sufficiency vs. Needing</td>
<td>[Now, I would talk to] Probably my parents. Or I might, uh--do--a look on the Internet, and then try to find out a number--phone number or email address and contact someone. I do, uh, through my, uh, former case manager, I do have someone in the Department of Social Services that I sometimes talk to, but she's very hard to get ahold of. [It’s less clear who to contact in an emergency, but that feels okay] Most of the time.</td>
<td>The only people I could talk to now would be my parents. Or I might look on the internet and try to find a phone number or email address to contact someone who might be able to help. My former case manager gave me the number of someone in the Department of Social Services that I sometimes talk to, but she's very hard to get ahold of. It's not really clear who can help in an emergency anymore, but that feels okay, most of the time.</td>
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<td>Support</td>
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<tr>
<td>Fear for the Future</td>
<td>[When my parents pass away] Um, [pause] it's going to be a shock and it's going to be a big change . . . And I--and I dunno [sic] how I'm going to handle it. I could have a relapse. [It causes me] A great deal, yeah [of anxiety].</td>
<td>When my parents pass away, it's going to be a shock and a big change. I don't know how I'm going to handle it. I could have a relapse. It causes me a great deal of anxiety.</td>
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<tr>
<td>Planning for the Future</td>
<td>Well, what I'd like to do is, um, set up this--uh--plan the estate so that I can have--um--keep the inheritance and keep my entitlements . . . And then have a--uh system that--there's a--there's a firm that is sort of like a firm for people--for seniors and also for the disabled. And, um, they have a lawyer, they have, um, they have people that do estate planning, they have--they cover just about every</td>
<td>What I'd like to do is plan the estate so that I can keep the inheritance and keep my entitlements. There's a law firm for seniors and the disabled and they have people that do estate planning. If I could get connected with them I think that they could probably help me manage my finances and also advise me in times where I might come into some sort of legal trouble or something. That happens a lot with disabled persons,</td>
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aspect of that. And, uh, if I could get, uh, connected with them I think that they could probably help me manage my finances and also advise me in times where I might come into some sort of legal trouble or something. And that happens a lot with people, uh, dis--disabled persons, they get into all kinds of legal problems [chuckle].

| Independence and Functioning | I am, uh, more independent now. [Pause] Um, in the past, um, I was dealing more with symptoms and just trying to function and I think that pretty much I, uh, moved beyond that. I went to--back to school and, uh, got--went, uh, got a--a culinary arts certificate and got involved with cooking and I found that the, uh, work, the cooking and doing work was not only, you know, financially lucrative, but it also helped me, uh, in terms of my symptoms, keeping busy and not thinking about my problems so much. | I am more independent now. In the past, I was dealing with more symptoms and just trying to function and I think that I've moved beyond that. I went back to school and got a culinary arts certificate and got involved with cooking and I found that the work was not only financially lucrative, but it also helped me in terms of my symptoms, keeping busy and not thinking about my problems so much. |

<p>| The Hospital | Deep breath] Let's see. [Pause] Well, I started out in the partial hospital program. So, um, they had a psychiatrist there and he would prescribe medication and then I would go to what are called &quot;groups,&quot; which are activities, within the building, and, um, that--that was sort of, um, a place where--you c--i--it's sort of like a hospital, sort | I started in the partial hospital program. They had a psychiatrist there and he would prescribe medication and then I would go to what are called &quot;groups,&quot; which are activities, within the building. The partial hospital program was a place where you're kind of recuperating. |</p>
<table>
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<tr>
<th>Independence and Functioning</th>
<th>of. Where you're kind of recuperating,</th>
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<tr>
<td>Independence and Functioning</td>
<td>and then, I moved beyond that, to the Clubhouse. Well, the Clubhouse is the Fountain House model, I believe, recovery model, and it's--and it's about, um, work readiness, and, um, being responsible, and being independent. Oh, it's def--they definitely have, uh, staff there. In the partial hospital, um, I--I was more a patient. At the Clubhouse, I'm an employee. Um, at the time of partial hospital, I think I needed it.</td>
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<tr>
<td>Independence and Functioning</td>
<td>And then I moved beyond that, and I joined the Clubhouse. The Clubhouse focuses on work readiness, being responsible, and being independent. In the partial hospital program, I was more a patient. At the Clubhouse, I'm an employee. But at the time when I was in the partial hospital program, I think I needed it.</td>
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<tr>
<td>Independence and Functioning</td>
<td>And, I think that, um, well wh--what really helped there was when they came out with, um, Zyprexa. And, um, that's--that was kind of the turning point for me, because before that the medications that I took had so many side effects that I wasn't really doing very well, mentally. Um, so, I--I needed that. And then when I moved on to the Clubhouse, um, I was glad to, uh, be a--a paid employee and earn some more money and be more independent. So that feels good, too.</td>
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<tr>
<td>Independence and Functioning</td>
<td>The thing that was the most helpful for me was when they came out with the medication Zyprexa. That was kind of a turning point for me, because before that the medications that I took had so many side effects that I wasn't really doing very well, mentally. Then when I joined the Clubhouse, I was glad to earn some money and be more independent. That feels good.</td>
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<tr>
<td><strong>Proving Myself to Others</strong></td>
<td>Some of them--some of the people that were at partial hospital, moved over to the Clubhouse. I think the director was the same person. Um, so, um, I sort of had to prove to this person that I was--that I was ready to go back to work. So, um, when I was at the partial hospital, I had to prove to this person that I was ready to go back to work.</td>
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<tr>
<td><strong>Transitioning from Patient to Employee</strong></td>
<td>and, um, so your--your question was, how--how--how did they, how--how did they, um, treat me? Or how did they--how do I interact with them differently? [Pause] I'm expected to be a, uh, competent employee at the Clubhouse. Yes, definitely. I'm--I'm what they call peer support staff. So, um, I am a member of the Clubhouse, but I'm--I'm also first and foremost an employee of the agency. So, it was a big transition to go from &quot;patient&quot; to &quot;employee.&quot;</td>
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<tr>
<td><strong>Belonging and Responsibility</strong></td>
<td>No, but I--I do--d--I do, um, talk to [peers] a lot in the course of the work, because we have people sign up to volunteer for diff--the various units. I'm in the culinary unit, so they will sign up for a task in the culinary unit, they don't get paid for it. They volunteer, and, um, they have to be shown what to do and I kind of, like, supervise them. So, in the process of working with them, sometimes they</td>
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<td>Topic</td>
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<tr>
<td>Will Talk to Me About Problems</td>
<td>I will talk to me about problems that they have and I will discuss it with them, but I'm not really supposed to get--do too much of that, because it's distracting from the work that I'm supposed to do . . .</td>
</tr>
<tr>
<td>Work and Responsibility</td>
<td>We’re preparing a lunch each day. And, there's a lot other responsibilities that I have just b--besides preparing the lunch, because I plan the menus and I do the shopping, and--and, um, uh, when we have parties, I help plan the parties, and . . . There's a lot of work involved. Um, I--I--typically [feed] around, um, it used to be 24 [people] a day, now it's kinda [sic] dropped off some days. Um, but, uh, up to like 24 or 30 people.</td>
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<tr>
<td>Wide Range of Recovery</td>
<td>I think that it's--there's a wide range of people [in different places in their recovery]. Some of them are--are n--are more debilitated, some of them are--are--actually went back to work and are working now. So it's a wide range.</td>
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<tr>
<td>Being Directed and Not</td>
<td>Yeah. Yes. [The director from the partial hospitalization] She--she was. Uh, she retired. So now there's a new director. Yes. [Sigh] Um, the former director was part of, um, an organization, I'm trying to think of the name of it, uh, Psycho-Social Rehab or The director of the Clubhouse who had come from the partial hospital program has retired now, so there's a new director. The former director was geared toward the rehabilitation model whereas the new director is definitely recovery model-oriented. The old director was the sort of</td>
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something like that? Which made me think that she was more geared toward the rehabilitation model. The new director is definitely recovery model-oriented. So, the--the old director was sort of, uh, a person that was sort of, um, she--sh--she liked to be very much involved in running things and directing people. Um, the new director is more where she just sits back and she lets you t--take over. So-so, that's basically the difference. Yes. And then she relies on my supervisor if I have any problems or questions, then she expects me--she says--she wants me to go to my supervisor, my immediate supervisor for that.

<table>
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<tr>
<th>Being Made to Feel Small</th>
<th>The two directors had very different personalities. The personality of the first director was more dictatorial. She was more emotional, sort of hot tempered, and she could get very angry. She had a way of making me very uncomfortable when I did something wrong. She would raise her voice and she had an angry tone. She just had a way of making me feel small, I guess you could say.</th>
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<tr>
<td>[They also differed in] Personality. The personality of the first director was more, um, [pause] let's see, [pause] dictatorial. Um, sh--she--she--she, um, she was more, um, emotional, hot--hot tempered sort of, she could get very angry. Um, [pause] well, she had a way of--of making me, um, uncomfortable, when she found--when I did something wrong, she made me very uncomfortable. Well, um, [pause] she, uh, raised her voice, she, uh, had an angry tone. Um, [pause] and, she just had a way of making me feel, um, small, I guess you could say.</td>
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<tr>
<td>Manager-Types</td>
<td>Well, the new director is sort of like that too, but in a different way. She--she--she's, uh, she's--she's a--she's a manager, what I call a &quot;manager-type,&quot; there were both &quot;manager-types.&quot; And, the second one is--I think she used to work at another clubhouse. And, so, um, she also has a--she has a s--a--two positions in the agency, she's not only a director of the Clubhouse, she's also, um, employment, uh, support. So, I think she helps people find jobs. So, um, she--she is, what I would call a &quot;manager-type,&quot; so that, you know, she--she definitely wants to keep things running smoothly and she wants to be authoritative.</td>
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<tr>
<td>Clients Need Authority</td>
<td>because if you don't, um, sometimes the people that I work with, the, you know, the clients, and different people that--there, they will--they will disregard what you tell them, unless you tell them in an authoritative way.</td>
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<tr>
<td>Staff are the Same</td>
<td>[Deep breath] [Pause] [The staff at the hospital and at the clubhouse] They're pretty--they're--they're very similar. In the way that they approach things. Um, they know how to talk to people with disabilities.</td>
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<td>Clients Need Authority</td>
<td>And, uh . . . Well, one--one piece of it is the disciplinary piece, because sometimes the--we--for example, um, we have people that, um, do th--are--aren't supposed to certain things, like, uh, they will, um, there's a designated smoking area. And sometimes they won't, uh, use it and they'll do different things, they'll throw their cigarette butts on the ground, and so they have to say--like the director will say, &quot;Well, you know, if you--if you put your cigarette butts--if you throw them on the floor or you throw them near the building, the building could catch fire.&quot; So, um, they have to be told, 'cus [sic] there--there--there's a wide spectrum of people in different places in their recovery. And they have to sort of be, um, disciplined somewhat.</td>
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<tr>
<td>What Staff Need to Do</td>
<td>um, so they have--they have to be able to handle that type of person. That type of client. You know, to kind of, like, direct them and help them--show them what to do. And, also, um, they have to have a patient side when they're trying teach something to a--a client, they have to be very patient with them and kind of work with them and, uh, help them, you know, supervise and help them--sh--show them what to do. Um, they are w-- [pause] yes [able to</td>
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<tr>
<td>Transitioning from Patient to Employee</td>
<td>With me not so much, but with them they are. They expect more out of me because I'm an employee. [My interactions with them look different because I am treated more as an employee than a client].</td>
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<tr>
<td>Transitioning from Patient to Employee</td>
<td>[Pause] Well, the psychiatrist at partial hospital, um, he was very stern, he came from the prison system. And, um, he had a bad temper. So, um, it was hard working with him an--and also--well one of the things that came up when I was in partial hospital was that they put me on some medications that didn't agree with me. And, um, when I asked to be changed to something else, they didn't--they didn't, uh, listen to what I said. Right. Th--they disregarded my input, so, um, it--it--I s--struggled for a long time with, um, side effects from the medications.</td>
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<tr>
<td>Transitioning from Patient to Employee</td>
<td>Um, in the new pl--in the--with my new, uh, psychiatric nurse, she listens very carefully to what I say, and luckily Zyprexa came out so the medication--that med--medication seems to agree with me, pretty much.</td>
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<tr>
<td>Transitioning from Patient to Employee</td>
<td>Yes. Also, I think that sometimes the, uh, other staff at the--at the partial hospital did not, uh, listen to, uh, my, um, needs or</td>
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requests, advice, um, um, for example, there was one time there where I, um, [pause] was talking to myself, I was hearing voices, and I was talking to myself. And they interpreted that as me not being able to drive home, so they took my keys away. And, um, the, uh, the, um, I-I--I want--I asked for the keys back and they would--they took away my--they took the keys away and they wouldn't give them back and I told them that I was going to go to the police station and complain that--ask the police to have them give my keys back. What instead happened is that I got taken to a psychiatric hospital. So, that's one example.

| The Hospital was a Dark Time | It was kind of a dark time for me, the partial hospital, it was--it was rough. Um, and we were also, uh, we did manual labor, um, it was--there were chores there also, so, the chores, I guess, were probably designed to help you in your recovery, but, um, it--it was difficult. Sweeping the floor, um, they had a, um, they have other things too. What did they have? Uh, mostly--I'm trying to think--uh--sweep--sweeping the floor, um, [pause] | It was kind of a dark time for me, the partial hospital. It was rough. We did chores there, which I guess were probably designed to help you in your recovery, but it was difficult. |
| Getting Involved with Cooking | they had a--a culinary block there, a culinary unit, that's where I first got involved with cooking. And, um, [sniff] so, there were chores | One of the chores was being assigned to the culinary unit at the partial hospital program. That's where I first got involved with cooking. |
within there [sic] where you-you would be assigned to prepare a certain dish, certain, uh, p--certain food. Um, I'm trying to think of what else were there chores.

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<tr>
<th>Belonging and Responsibility</th>
<th>I think we--we had a, um, we had a--a--I think what was called a &quot;consumer council,&quot; we had like a president, a vice-president, stuff like that. I was, uh, president of the co--of the, uh, uh, hospital for a while - partial hospital - so, I--I would--I would sort of run meetings with the--with the patients there. Clients, I guess they call them more than--more than patients. But, I would run the meetings. At the partial hospital program, we had what was called a &quot;consumer council,&quot; with a president, a vice president, and stuff like that. I was president of the consumer council at the partial hospital program for a while, so I would sort of run meetings with the patients there. Clients, I guess they call them now, more than patients.</th>
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<tr>
<td>Staff are Different and the Same</td>
<td>So, um, you asked me what the difference was between the partial hospital and the Clubhouse? With the staff. Um, [pause] I think--I think that the staff at the Clubhouse are [pause] better suited to the Clubhouse and the people at the partial hospital, some of them were not well suited for, uh, mental health, uh, treatment. Um. Um, they--they--they didn't--they weren't, uh, sensitive to the, uh, s--uh--clients--sensitive to the clients. [At the clubhouse] They're more sensitive to our needs and so forth. Although, um, in both places there is kind of a dictatorial side to it. I think that the staff at the Clubhouse are better suited to the Clubhouse and the people at the partial hospital, some of them were not well suited for working in mental health treatment. They weren't sensitive to the clients. At the Clubhouse, they're more sensitive to our needs and so forth. Although, in both places there is kind of a dictatorial side to it.</td>
</tr>
<tr>
<td>Rules and Consequences</td>
<td>Um, because, like I said before, um, people--some of the--some of the members will misbehave. And, uh, w--they set up--wh--a, uh, they set up a, uh, what's it called, um, a r--rules committee. So they have what they call a &quot;matrix of rules.&quot; So, a--at some point - this is in the past, I don't think they have this anymore - but they had a system where if you broke a certain rule, then there was a certain consequence. And, the first consequence might be suspension for a day. And then maybe it would be a week or a month, and then finally, the final consequence would be total, you know, permanent suspension. From the program.</td>
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<tr>
<td>A New System</td>
<td>So, um, they did that for a while, but then somehow they decided that they wanted to try this new system where the person would sort of, like, have a, uh, somebody counsel them about the problem - this is s--a recent development - they're--coun--being counseled about the problem, and, um, they're shown ways that they could do things differently, so that they wouldn't, uh, cause a problem. I don't know yet because it's a rec--it--they just changed over to the new system.</td>
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<tr>
<td>Being Advised Instead of Punished</td>
<td>So . . . Very recently, so, I don't--I don't know. [Pause] It's hard to say. I think there's a few people there that maybe not--will not respond. But, uh, for the most part I think that, uh, there's--there's a lot of women in the program and I think that the women might respond better, um. Um, I--I think--I think that, um, I have a feeling that it--if--and just a--just a hunch that it--it probably, uh, will make some people more comfortable. The fact that there--there isn't a punishment for their behavior. Instead of a punishment, they are actually guided as to--or advised as to what to do. I think there's a few people at the Clubhouse that maybe will not respond will. But, there's a lot of women in the program and I think that the women might respond better. I have a feeling, just a hunch, that the fact that there isn't a punishment for their behavior, will make some people more comfortable. Instead of a punishment, they are actually advised as to what to do.</td>
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<td>Um, I started around 1989 [in the hospital]. Mm, yeah. I--I got out of partial hospital--I--I think I started going to cooking school around '93, so from '89 to '93, I was at the partial hospital program around 1989 and was there until 1993.</td>
<td>I started attending the partial hospital program around 1989 and was there until 1993.</td>
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<tr>
<td>and then '93-'94, I was, um, going to cooking school and also I was working part time with my father in--in electronics, 'cus I have an engineering degree. I have a bachelor's of science in electrical engineering, so I was working as a technician-electronics technician for the same company that my father worked for. I probably could have gone there, uh, f-pa--uh, full time and worked there full time, but Between 1993 and 1994, I was going to cooking school and working part time with my father in electronics. I have a bachelor's of science in electrical engineering, so I was working as an electronics technician for the same company that my father worked for. I probably could have worked there full time, but they went out of business. I think they were bought out by another company and then they moved out of state.</td>
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<td>Category</td>
<td>Description</td>
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<tr>
<td>Transitioning from Patient to Employee</td>
<td>Yeah. So, around '95 or so, I was--I was there on stipend, at the Clubhouse. And, um, then in '98, I think that's when I was formally, um, hired as s--staff.</td>
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<tr>
<td>Stability &amp; Security</td>
<td>Well, I feel like I have a marketable skill as a chef. So, I feel like if I--if something happened, um, or some--some--for some reason the program closed or if I was laid off, or something like that, that I could get work as--as a cook. [So there's a sense of stability and security].</td>
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<tr>
<td>The Safety of Disclosing</td>
<td>Oh, I can say something else, too. I like the people that I work with there. Um, I did have some trouble when I was working in--outside of the, uh, agency. Some people--I--I tend to disclose my illness to them and what happened was--is that I--I was, uh, abused because of that. Uh, people actually, kind of, um, for some reason they--they put me down, because I was--I had a disability. No, [the clubhouse is] a very safe place. For the most part, people understand where you're coming from.</td>
</tr>
<tr>
<td>Limited by My Disability</td>
<td>[Pause] For the most part, um, well, um, I do get a sense from the [staff] that--that my disability does limit my--my work ability somewhat. I--I--I feel like I'm running up--running up against limitations, in terms of like remembering things. So, I have to try to write everything down because, uh, when they give me a lot of information, sometimes I can't remember it all and then sometimes I will forget it, that I had to do certain things. So, when that happens sometimes I--I get criticized.</td>
</tr>
<tr>
<td>Doing a Good Job</td>
<td>but for the most part, they do a, uh, yearly evaluation of me, and my evaluation was like, near the top, like five was the highest mark and most--a lot of them my--my marks were in the fives or fours. I--I feel good, I--I feel like I'm--I'm doing a good job.</td>
</tr>
<tr>
<td>Work-Readiness rather than Emotional Support</td>
<td>however, I do feel somewhat limited by my disability. [Pause] [I'd prefer that] Maybe [they] n--not be so, uh, judgmental or critical when I make a mistake. But, at the same time, I think they're trying to create an environment where you would--trying to simulate what you what you would f--experience in the community, if you had a job out there.</td>
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<td>Section</td>
<td>Description</td>
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<tr>
<td>In a Safe Place</td>
<td>Um. [Pause] I--I feel like I'm in a safe place where I am. I feel more secure there. I feel like if I were able--if I were to leave that environment and go out into the community, that I--I might be treated in the same way I was before, where I was sort of, uh--sort of, uh, put down or--or maybe in a--in a situation where, let's say, I had--was having some kind of psychotic symptom that they may not understand what's going on and there--that there might be some kind of, uh, serious consequence to that.</td>
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<tr>
<td>Independence and Functioning</td>
<td>No. Well, in terms of my work readiness, I think my work readiness is better; I think I can work better now and my symptoms are more under control. So, from that standpoint, I think that I'm--I'm more ready for work, and that's basically the community interaction that I think of as w--the workspace.</td>
</tr>
<tr>
<td>Belonging and Responsibility</td>
<td>Yes, I'm--I'm, uh, involved with my, uh, Catholic Church. I'm deeply involved in my church community and also in a local mental health advocacy organization. So, um, that--that was--that was really good, that--they gave me a lot of confidence, too.</td>
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<tr>
<td>My Confidence Comes from Myself</td>
<td>[Pause] I think that my confidence comes from within myself. Um, I don't think that the program gave me confidence so much, but</td>
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<tr>
<td><strong>Transitioning from Patient to Employee</strong></td>
<td>I think that the program gave me stability.</td>
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<td></td>
<td>Yeah, I--I had been, uh, laid off from a number of jobs prior to that. When I tried to work as an engineer. Um, I--I--I--I worked--I was hired, uh, by a company right out of college and I--my father and sister both worked there also. And, um, I had a nervous breakdown while I was there. So, that's when I was hospitalized and then I saw the doctor for a while, the psychiatrist that--at the hospital. And then, I tried to get back into engineering, I--I actually, uh, had a--a--a Korean neurosurgeon, acupuncturist, psychiatrist. He was--he gave me acupuncture. And, um, I tried--I--I--I felt like I was well enough to work as an engineer. I worked for a company, uh, I was on--I was on probation--a probation period, they were trying me out, and at the end of that period, I didn't, um, [pause] live up to their expectations, so I was laid off.</td>
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<tr>
<td><strong>[Pause]</strong> Yes. Um, [pause] I work--my--my cul--the culinary unit program has a very tight budget. And, we get a lot of food from a place</td>
<td>So, um, I was coming from a place, before the Clubhouse, I was coming from a place where I felt like I wasn't succeeding in--in working--my work.</td>
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<td></td>
<td>The culinary unit has a very tight budget. We get a lot of food from a co-op of sorts. What happens is that different restaurants and, maybe,</td>
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where you can--it's like a co-op sort of. And, um, they--what--what happens is, is that I think different restaurants and different, maybe, supermarkets, they donate food to them, ex--surplus foods or foods that they w--don't want. And we get it for a reduced price, sometimes for free.

Wanting to do More

Um, the food that we get, I don't feel is healthy, but I think there's--I--I'm--I'm kind of a vegetarian myself, so it's kind of strange being a chef as a vegetarian, but--they're--it seems to me, they're--they're more interested in, like, meat and so I--we serve a lot of meat. And, um, I feel like the meals that I'm preparing are not really the healthiest meals, and I feel like, that the food aspect, what you take into your body has a lot to do with how much you recover. So, um, I think that what we don't really get as man--as much fresh vegetables as I would like, and I think that we have to cu--I have to really cut a lot of corners when I'm preparing the lunch. So, I--I feel like I am feeding them, but a--at the same time I--I feel guilty that I'm not feeding them the way I would like them to be fed. The food that we get, I don't feel is healthy. I'm kind of a vegetarian myself, but it seems to me that the clients are more interested in meat and so we serve a lot of meat. I feel like the meals that I'm preparing are not really the healthiest meals, and I feel that what you take into your body has a lot to do with how much you recover. We don't get as many fresh vegetables as I would like and I have to really cut a lot of corners when I'm preparing the lunch. So, I feel like I'm feeding them, but at the same time I feel guilty that I'm not feeding them the way I would like them to be fed.
I was 23 when I was first hospitalized and now I'm 55. Let me see, there was the Hospital, and then I saw the acupuncturist for a while, that was two, and then, this, the agency where I'm at now is three, so I think three. Oh, also there was a private psychiatrist that the company where I worked for, when I had the nervous breakdown in '83, they sent me to a private psychiatrist. So that's maybe four. I hope I answered your questions adequately.
Participant 2: Leah

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<thead>
<tr>
<th>Themes</th>
<th>Meaning Units</th>
<th>Transformation 1</th>
<th>Transformation 2</th>
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<tr>
<td>A good therapy relationship</td>
<td>Okay, um [pause] after a bit of a hiatus of, uh, maybe two to three years, I just reentered therapy.</td>
<td>I've just reentered therapy after a hiatus of two to three years.</td>
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<tr>
<td>Trauma</td>
<td>To, um, because I'm still dealing with residual post-traumatic stress, um, problems and, uh, uh, fear related to a, um, uh, health, um, situations.</td>
<td>I made the choice to reenter therapy because I'm still dealing with residual post-traumatic stress and fear related to some health situations.</td>
<td>I reentered therapy because I'm still dealing with residual post-traumatic stress and fear related to some health situations.</td>
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<tr>
<td>A good doctor</td>
<td>And, so--and then I also see a psychiatrist, um, out of, uh, town and I will tell you why later on. [The psychiatrist works] Independent.</td>
<td>I also see an independent psychiatrist who works outside of town.</td>
<td>I also see an independent psychiatrist who works outside of town.</td>
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<tr>
<td>A good therapy relationship</td>
<td>Well, I just started again. So it's, um, I—I will say I went not knowing if it was gonna be, you know, a good match. [It is] Absolutely. Just a joy. And she has a private office, but was on the third floor, so she agreed to see me in an office that she started out in in her home. So it's more accessible. And she and I are just on the same page. We both love photography, she's got photo--her photographs all</td>
<td>I will say, I went to therapy not knowing if it was gonna be a good match. It absolutely is. It's just a joy. The therapist has a private office, but the office was on the third floor, so she agreed to see me in a home office that was more accessible. She and I are just on the same page. We seem to enjoy a lot of the same things, we both love photography and music. She has her photographs all around. So it's just so fun and she's so non-</td>
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around. And, um, just a lot of things that we seem to enjoy, music and things that we both like. Yeah. So, it's just so, like, so fun and--and she's so, like, non labeling, just kind of, uses--not even, barely--I don't even see the DSM sitting around her office, so. I like that.

Trauma

[I was hoping to address] As I said, it was--I've had multiple, multiple, multiple, [laughs] uncountable traumas in my life. Sexual and--and, uh, losses and hospitalizations and treatment that was not good and, um, [pause] I've been in two fires. Yeah, so lots of things. Yeah, 'cus I keep running up against it. I just seem to get over it and then something else comes in my face and brings it up. I have screaming nightmares.

As I said, I've had multiple, multiple, multiple, uncountable traumas in my life. Sexual traumas, losses, hospitalizations and treatments that were not good, and I've been in two fires. I just keep running up against the trauma. I seem to get over it and then something else comes up in my face and brings it up. I have screaming nightmares.

A good partner

and I said to my partner, who's very low-keyed about the whole thing, he said--I said, "Honey, do you think I should go see somebody?" He never said yes before and he said, "Yeah, I think so." He's wonderful. He's

I said to my partner, who's very low-keyed about the whole thing, I said, "Honey, do you think I should go see somebody?" He'd never said yes before, but this time he said, "Yeah, I think so." He's wonderful.
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tbody>
<tr>
<td>A good doctor</td>
<td>I only see the psychiatrist about every three months. I can always call her, but I'm not dependent on her in any way. We just get along well and I respect her and she respects me. She lets me guide how things are going to go. I've been working with her since about 2011, on and off.</td>
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<tr>
<td>All hell broke loose</td>
<td>I began working with her after all hell broke loose. I had been doing really well and then all hell broke loose.</td>
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<tr>
<td>Beginning to thrive</td>
<td>I was beginning to thrive when I got hired at a local mental health advocacy organization. I was not thriving before I got hired there, I was beginning to but, um,</td>
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<tr>
<td>My strengths</td>
<td>I have a background in oral history, writing, literature,</td>
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and literature and, uh, social services work, and in just personal interests.

and social service work.

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<tr>
<th>The bad doctor</th>
<th>And, uh, I had a psychiatrist who I had seen for many, many years. Many years. Many years. And I had trusted him as you--one would, um, and well, this was the days when psychiatrists would spend more time rather than just medication. So, and--it was beginning to shift. Anyway, I completely trusted him. Then all of the sudden he started saying that he wanted me to call him by his first name and then he would make little comments like, &quot;Why don't you color your hair like all the other women?&quot; And he started getting flirtatious, but I kind of brushed that off.</th>
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<td>I had a psychiatrist who I had seen for many, many years. And I trusted him, as one would. This was back in the days when psychiatrists would spend more time, rather than just doing medication, but that was beginning to shift. Anyway, I completely trusted him. Then all of the sudden, he started saying that he wanted me to call him by his first name and then he would make little comments like, &quot;Why don't you color your hair like all the other women?&quot; He started getting flirtatious, but I kind of brushed that off.</td>
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<tr>
<th>Wonderful support</th>
<th>a--anyway, long story short, I'll try to be succinct, it's hard, but I'll be succinct as I've gone over this a million times with the team at work and the people there gave me wonderful support.</th>
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<td></td>
<td>It's hard, but I'll be succinct, because I've gone over this a million times with the team at my work and they gave me wonderful support.</td>
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<tr>
<td>Very good support</td>
<td>Um, I was home after--I've had four joint replacements and I was having terrible pain after this knee replacement. I was working and--and had very good support at work, I was allowed to work from home when I was able, when I got better enough. And, um, they allowed me to adapt my schedule, et cetera.</td>
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<tr>
<td>The bad doctor</td>
<td>Um, so, uh, surgeons cut off your pain medicine, uh, and I was in excruciating pain, so he said to me--and he worked at a very highly respected, um, hospital [laughs]. But, um, he saw me there and he started--he said, &quot;I believe in pain control. I really believe in pain control.&quot; So, he started coming to my apartment and he--you know, it's very professional; he'd give you the pain meds and dudda dada da. So, when I was able to start walking a little bit, I'd walk him to the door, which was just, you know, it was just on one level and I'd walk him out to the parking lot and</td>
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<td>Event</td>
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<td>He'd give me like a bear hug. Well, the bear hug started getting nuzzle-y. In my neck. And close and pressing. And also became suspicious about the pain medication. And, I won't dis- [pause] evolved.</td>
<td>1. 255</td>
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<tr>
<td>God-awful reflection</td>
<td>And after a time, I became fully aware, after a lot of god-awful reflection and what the hell do I do and who do I turn to. And, uh, I went to visit my family; I spent most of the time holed up in the-- in my room. I was crying and--about things that they didn't know, they didn't know exactly what I was doing then, they thought I was just, you know, reading or something. I mulled it over a lot. And I got enraged. I said, &quot;This is really, really bad.&quot;</td>
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<tr>
<td>Support</td>
<td>And, uh, I realized I had to do something and I came home and I did have a therapist at the time, thank God almighty a woman, and she knew him. And she supported me and I got support here.</td>
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<td></td>
<td>After a time, I became fully aware of what was happening. I did a lot of god-awful reflection and &quot;what the hell do I do&quot; and &quot;who do I turn to.&quot; I went to visit my family and spent most of the time holed up in my room crying. They didn't know exactly what was I was doing, they thought I was just reading or something. I mulled it over a lot and I got enraged. I said, &quot;This is really, really bad.&quot;</td>
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<td>I realized I had to do something and I came home. I did have a therapist at the time, thank God almighty it was a woman, and she knew the psychiatrist. She supported me and I got support at work as well.</td>
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<tr>
<td>Taking action</td>
<td>And I happened to be in a DBT program at the same hospital simultaneously, 'cus I was starting to slide, but I wasn't identifying exactly what was going on. I went in for the second time and I said in the intake, &quot;Somebody on staff is abusing me. And he's diverting meds.&quot; So the next--I thought they were just going to gloss over it. So the next time I came in, the Director of Medicine was there. Or the Director of Something, a bigwig. And I--I thought, well this is interesting, 'cus they usually have a resident or somebody I didn't think much about. He said, &quot;Tell me. Right now. Tell me what is going on.&quot; I told him.</td>
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<tr>
<td>Terminating</td>
<td>He said, &quot;You can choose to do one of two things. You can write him a letter and terminate. And we will take over. Or, you can terminate yourself, in person.&quot; So I mulled that over. I terminated. Walked in--took--me a f--little bit. And I walked into his office and I stood there. This was like--</td>
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<tr>
<td>The bad doctor</td>
<td>I mean he had been a com--he's like, &quot;I can't imagine life without you&quot; in our appointment. I mean it's really--it was getting out--out of control.</td>
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<tr>
<td>I stood proud and tall</td>
<td>And I walked--I walked into his office and said, &quot;You have&quot;--I stood like proud and tall and I said, &quot;You have done harm.&quot; You know, the Hippocratic oath. And, I said, &quot;Dr. So-and-so knows and he knows you've been&quot;--I said, &quot;You know, you've been taking those medications and diverting them. For yourself.&quot; And he blanched. And I said, &quot;And Dr. So-and-so is going to be speaking with you.&quot; And he blanched and leaned back in his chair and said, &quot;I'm sure he is.&quot; I said, &quot;I never want to see you again or talk to you. I am done and I'm outta here.&quot; And I walked out.</td>
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<tr>
<td>A nightmare scene</td>
<td>And then they took over. And they brought him before the ethical board and he admitted everything. I got interviewed by the Department of Public</td>
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<tr>
<td>A raw mess</td>
<td>I ended up going down the tubes myself. I turned into a raw--quote unquote raw mess. I couldn't find anybody to help me, I didn't want anybody from around here.</td>
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<tr>
<td>Finding help</td>
<td>I got out of Dodge, as it were, and—and got linked with my doctor out of town.</td>
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<td>I take great pride</td>
<td>I am too. I take great pride in that [telling]. After--I've been abused many times, sexually. It's like, okay, I ain't gonna have this jerk, um, no no, no, no, no, no. So, um. First it's compassion, &quot;Oh, I want him to get help.&quot; Oh, right. And then it took me about-and I changed my mind real fast. [Inaudible, 12:22:21]</td>
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<tr>
<td>A nightmare scene</td>
<td>I sued him and it got settled out of court. It was a nightmare scene. Had to go, like, multiple times to be interviewed by the forensic psychiatrist</td>
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and it was god-awful, but I survived. But, that's that story. Talk about abuse by the system, there we go. It was about as bad as you can get. Yes. Yes.

A raw mess

I ended up in intensive outpatient. I mean, I couldn't even barely drive back and forth I was so--I'd have to stop the car and get off the highway. I was so raw. I--I keep saying that word, but I was. Yeah, but they wouldn't let me talk about it. They didn't want to upset other patients. [Pause] So, that was that.

My own input

[I've been in treatment] Since I was 14. [how does the care you're getting now feel different from care you've gotten in the past?] Um, [pause] day and night. The kindness, the, um, letting me have my own input, um, you know f--I'm still on a little bit of medication. But I discuss it with, uh, the--the doctor and she--psychiatrist and she says, "Well, what do you think?" She--

forensic psychiatrist

and it was god-awful, but I survived. Talk about abuse by the system, there we go. It was about as bad as you can get.

I ended up in an intensive outpatient program. I mean, I couldn't even barely drive back and forth. I'd have to stop the car and get off the highway. I was so raw. I keep saying that word, but I was. The intensive outpatient program wouldn't let me talk about what had happened. They didn't want to upset other patients. So, that was that.

I've been in treatment, on and off, since I was 14. The care that I receive now compared to the care I've received in the past is like day and night. The kindness and letting me have my own input. I'm still on a little bit of medication, but I discuss it with the psychiatrist and she says, "Well, what do you think?" We talk and she let's me give input.
you know--we talk-- she let's me give input.

<table>
<thead>
<tr>
<th>A zombie</th>
<th>Before, I was a frikking over-medicated zombie. I was obese. When I started volunteering at the advocacy organization, I was a zombie. I could barely speak because my mouth was dry, dry, dry.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before] I was a frikking over-medicated zombie. I was obese. Uh, I couldn't talk ‘cus my mouth was--when I started volunteering here, I was a zombie, my--practically. My mouth was, you know, dry, dry, dry. I could barely speak.</td>
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<tr>
<th>Inside myself</th>
<th>I had no clothes, you know. I had the history behind me and [pause] there was a time period where I didn't even talk. I mean, I might of--I said a little bit, but I just completely [pause] was into myself.</th>
</tr>
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<tbody>
<tr>
<td>Um. I had no clothes, you know. I had the history behind me and [pause] there was a time period where I didn't even talk. I mean, I might of--I said a little bit, but I just completely [pause] was into myself.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Early support</th>
<th>When I was 14, my mother finally picked up that something was wrong and linked me with a psychiatrist. The psychiatrist was really my only friend.</th>
</tr>
</thead>
<tbody>
<tr>
<td>But going back to when I was younger, um, I had my first experience was with a p--woman--psychiatrist, my mother finally picked up--it was early, I mean this was early history--and she picked up that something was wrong and linked me with a psychiatrist. And she was really my only friend.</td>
<td></td>
</tr>
<tr>
<td>A nightmare</td>
<td>[Inaudible, 00:15:26] and then my fam--we got uprooted from one--from the state we lived in and we went back to the city where I was born and then my father had mental health issues too, hospitalized, hospitalized, hospitalized, ended up in the state hospital. And it was a nightmare. And my family fell apart. We left in the middle of the night, my mother, sister, and I. Left my house, my dog, everything I owned. Came back to here. No place to live, we stayed with my aunt and uncle.</td>
</tr>
<tr>
<td>I was an activist</td>
<td>And, uh, um, I went to sch--senior year I did pretty darn well. And, uh, I got involved as an activist in the civil rights movement. This is right before, uh, 1960--64, so it was right before the civil rights act got passed. And I mean I was really an activist.</td>
</tr>
<tr>
<td>Raped</td>
<td>But, uh, I also subjected mysel--I was like, promiscuous. Very, very promiscuous. And I ended up getting raped. But I blamed myself and</td>
</tr>
</tbody>
</table>
wouldn't tell anybody. "It's my fault," 'cus I let my so-called "boyfriend," who fathered a child--my child, my daughter that I had. And, first of all, the father was married and I had no clue, no clue. And he--he abused me, frankly. Yeah. Forced oral sex, all kinds of stuff.

| Raped          | And then, one night--I--we had an apartment with a friend--one night, his, um, nephew came. He said he wanted a place to stay. My neph--part--my roommate was away. I said sure, I liked him, wake up in the middle of the night, he's on top of me. So, you know, it's blame, blame, blame. And then it was just-- |
|               | We had an apartment with a friend and one night his nephew came to visit. He said he wanted a place to stay. My roommate was away and I liked the nephew, so I said sure. I wake up in the middle of the night and he's on top of me. So, you know, it's blame, blame, blame towards myself. |

| Raped          | I got raped by this--my first boyfriend, when I was 14. And, I mean, he's my boyfriend, right? Raped. So--and multiple things related to that. And I've had a history of several rapes. Nothing in the family, but rapes, rapes, and more rapes. Molestations. |
|               | I got raped by my first boyfriend, when I was 14. And, I mean, he's my boyfriend, right. Raped. I've had a history of several raped. Nothing in the family, but rapes, rapes, and more rapes. |

| Doing pretty darn well | [I wasn't in treatment after we moved in | After we moved in with my aunt and |
| My baby | And then I got pregnant with my daughter, I went to all these different places, first here and then out of state, and then ultimately a home for unwed mothers. And, um, I realized they're not going to let me keep my baby. They're not going to let me keep my baby. Nobody was offering supports. So I threatened suicide. I wasn't going to give her up. I didn't know it was a she, I wasn't going to give my baby up. No way. |
| A psych unit | But I started getting, um, I don't know if I just made it up or if was acc--true but they came and got me of course and they brought me home, my mother, to g--you know they're going to st--they, um, committed me. 'Cus of the threat. Yeah, I was pregnant. They committed me. So, here I was in the ancient--it was a city hospital. It was--this |
| uncle, I wasn't in treatment. I was doing pretty darn well. | When I got pregnant with my daughter, I went to all these different places, first here and then out of state, and then ultimately to a home for unwed mothers. And I realized that they weren't going to let me keep my baby. Nobody was offering supports. So, I threatened suicide. I wasn't going to give my baby up, no way. |

| A psych unit | I don't know if I made it up that I was suicidal or if it was actually true, but my family came and got me of course and they brought me home and then committed me because of the threat. So here I was, in this ancient city hospital. I'm eight months pregnant on a psych unit. This was in the 1960s, so there was this long, dark hallway. There were |
is in the 60s. So it's like this long, dark hallway—we're—I'm on a psych unit, I'm pregnant. I'm nine-eight and a half-eight months pregnant. And here I am, knowing I'm going to lose my child—that's all I'm doing, I'm cry—I'm freaking out, because I'm going to lose my baby. So they put me in—and I wasn't really going to commit suicide. I just said it 'cus I just want my baby, okay. So, um, they put me in this hellhole. I was hysterical. All I did was cry. Cry, cry, cry, cry. There were nuns there, sitting on the edges of their bed. And here I am, knowing I'm going to lose my child. I just said it because I wanted to keep my baby. So they put me in this hellhole. I was hysterical. All I did was cry. It was just god-awful.

No support, just horror

[And how did the people who worked there, how did they treat you, how did they interact with you?] All—nothing. All I did was sit in my room and then, uh, I mean suppose they—you know—I got food stuff and stuff, I don't remember that part. I just remember the horror of it. And I did not remember any interaction with the people who worked there. All I did was sit in my room. I mean, I suppose I got food and stuff, but I don't remember that part. I just remember the horror of it. And I do remember, finally, seeing a psychiatrist. I got hysterical with him, sobbing, sobbing, sobbing.
<table>
<thead>
<tr>
<th>I was savvy</th>
<th>So I said, the hell with this, I am not staying here. So, um, I got, uh, a--a pad, Kotex or something, whatever they called them then. [Laughs] Now. Anyway, and I put a little nick in my arm, somehow, with something, and I put the blood on the pad. I was savvy; I dunno how I even thought of that. Like, so, I thought--and so--you know what they did? They took me out. They put me on a regular unit, because they thought I was bleeding. Obviously I was okay [laughs] and they sent me--they found som--a little home, a house, it was like a foster home kinda thing. They put me in that until I gave birth.</th>
<th>So I said, the hell with this. I am not staying here. I got a Kotex pad and I put a little nick in my arm, somehow, with something, and I put the blood on the pad. I was savvy; I dunno how I even thought of that. And you know what they did? They took me out. They put me on a regular unit, because they thought I was bleeding. Obviously I was okay and eventually they found a foster home kinda thing. They put me in that until I gave birth.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I lost her</td>
<td>And I had to surrender my little girl. I took care of her in the hospital, I held her for--they kept you</td>
<td>I took care of her in the hospital and I held her. They kept you for like four or five days then. Then I</td>
</tr>
<tr>
<td><strong>I just couldn't function</strong></td>
<td>But so I have to say that was god-awful. And then, I just couldn't function. And so I ended up going--just staying home, sitting on the couch.</td>
<td>After that, I just couldn't function. I ended up just staying home and sitting on the couch.</td>
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<tr>
<td><strong>Trying to work</strong></td>
<td>I f--finally got to the point that I wanted to find--try to work. I went to work.</td>
<td>Finally, I got to the point that I wanted to try to work.</td>
</tr>
</tbody>
</table>
| **Raped**                     | Oh I got--I had worked for a dentist too, I forgot that part, right out of high school. He wanted to hire me. I was ready to go home from work one day and he comes out with semen on his pants from the lab, and he goes, uh, "Here, this smells wonderful, wanna try?" He smothered me with chloroform to--to be sexual with me. He was a married man. I mean, this sounds outrageous. This is not hallucination, this is fact. Fact. And there's a picture on the wall, right in the waiting room, of his wife and his children while he's doing this. I kept saying, "I'm dying, I'm dying." I felt like I was dying! Maybe I worked for a dentist, right out of high school. He wanted to hire me. I was ready to go home from work one day and he comes out from the lab with semen on his pants, and he goes, "Here, this smells wonderful, wanna try?" He smothered me with chloroform to be sexual with me. He was a married man. I mean, this sounds outrageous. This is not hallucination, this is fact. Fact. And there's a picture on the wall, right in the waiting room, of his wife and his children while he's doing this. I kept saying, "I'm dying, I'm dying." I felt like I was dying! Maybe I
<p>| dying, I'm dying, I'm dy'--I felt like I was dying! Maybe I was, I dunno. He held this rag--to this day I can't stand that smell. It freaks me right out. So, anyway. That's that lovely story. was, I dunno. To this day, I can't stand that smell. It freaks me right out. |
|---|---|
| To the state hospital | Yeah, then I ended up--I couldn't do the job, went home and took a bottle of aspirin. Called my mother and said I'd overdosed with aspirin. So they put me in the state hospital. 19. I couldn't do the job, went home and took a bottle of aspirin. Called my mother and said I'd overdosed with aspirin. So they put me in the state hospital. I was 19. |
| Horrific | It was so institutionalized, it was horrific, I mean--I mean, life in the state hospital? The beds were like this far apart. People were hallucinating and crying and sobbing all night. We wandered around the day room--just like, you know, what a--the stereotypical wandering around the day room. Um, people could smoke so there's a little thing on the wall so they light their cigarettes. There's no place to sit. There's one couch that every--or two that everybody's vying for. Um, I'll just say there was one person that--perhaps It was so institutionalized, it was horrific. The beds were so close. People were hallucinating and crying and sobbing all night. We wandered around the day room, you know, the stereotypical wandering around the day room. People could smoke, so there's a little thing on the wall so they could light their cigarettes. There's no place to sit. There's one or two couches that everybody's vying for. I got shock treatments with no freaking anesthesia. There was one person, or perhaps two, that were kind. |</p>
<table>
<thead>
<tr>
<th>Category</th>
<th>Text</th>
<th>Text</th>
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<tr>
<td>two, that were kind. Everybody else was just like horrible. It was just--a--and I got shock treatments with no freaking anesthesia.</td>
<td>Everybody else was just horrible.</td>
<td></td>
</tr>
<tr>
<td>Treatment began to get better</td>
<td>[The next treatment I received] I think it was, um, yeah, I think it was locally. Oh no, they--I tri--I tried to work. I got--I don't know, I can't keep track of sequential--but, anyway, I--I got--I was in and out of, um, a city hospital. It was a nice unit, um, I'll just say. It was certainly a bet--way better, but, um,</td>
<td>The next time I received mental health treatment was local. I was in and out of a city hospital. I'll just say it was a nice unit. It was certainly way better.</td>
</tr>
<tr>
<td>My children</td>
<td>I ended up getting married and guess what? I turned around. Everything was great. And, uh, I was happy and I still didn't have my daughter, but I had my son. I had my first child. And my second child.</td>
<td>I ended up getting married and things turned around. Everything was great. I was happy. I still didn't have my first child, my daughter, but I had my first son and then my third child.</td>
</tr>
<tr>
<td>Cried myself to sleep</td>
<td>But, my husband turned out to be a severe abuser of alcohol. And I had no clue. On our honeymoon, the second night, he got</td>
<td>But, my husband turned out to be a severe abuser of alcohol. I had no clue until our honeymoon. The second night, he got flat out drunk</td>
</tr>
<tr>
<td>Treatment varied</td>
<td>So, you know, I'll say syst--a--system was starting to improve. Ah, it varied. It varied.</td>
<td>Treatment varied, it varied, but the system was starting to improve.</td>
</tr>
</tbody>
</table>
Participant 3: Dinah

<table>
<thead>
<tr>
<th>Themes</th>
<th>Meaning Units</th>
<th>Transformation 1</th>
<th>Transformation 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Treatment</td>
<td>Um, I see a--a--I--I guess it’s--um--I see a psychiatrist. I'm not in therapy that I go to once a week, right now.</td>
<td>I see a psychiatrist. I'm not in therapy right now.</td>
<td>I'm not in therapy right now.</td>
</tr>
<tr>
<td>My Last Therapist</td>
<td>Um, only because the therapist that I was seeing--I w--I wasn't--I would say I wasn't even seeing a therapist once a week, I was seeing her more like once every two weeks or three weeks, um, just to, um, work on some areas that I felt needed addressing, um, like, um, weight issues and also--um--just some unresolved issues. So I stopped seeing her because she left the agency and went to work somewhere else and I haven't yet pursued it.</td>
<td>The therapist I was seeing every two or three weeks left the agency to work somewhere else and I haven't pursued beginning therapy again.</td>
<td>The therapist I was seeing every two or three weeks left the agency to work somewhere else and I haven't pursued therapy since then.</td>
</tr>
<tr>
<td>Current Treatment</td>
<td>And--and--and it's something that I may pursue again, but I spent a long time in therapy already. So I see a psychiatrist for medication management.</td>
<td>It's something that I may pursue again, but I spent a long time in therapy already. So, for the moment I just see a psychiatrist for medication management.</td>
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</tr>
<tr>
<td>Treatment Location</td>
<td>They're both at the same site, yeah. It's a local, um--well it was part of my catchment area originally, so it's a local mental health or behavioral health care system--service, um, that, um, reaches a lot of regions. So, it's a--it's a--I don't even know if I would call them LMHA necessarily, which is a local mental health authority, but they--they do reach--they are that far reaching and they're funded in part by the Department of Mental Health and Addiction Services, so it's one of those facilities. Probably it is considered a LMHA unless you're . . . [But the only service you're receiving through them right now is the psychiatrist] Psychiatry. Yup, yup.</td>
<td>My psychiatrist and the therapist I was seeing were both at the same site. The site is a local mental health or behavioral health care service that reaches a lot of regions. I don't know if I would call them a Local Mental Health Authority, but they are that far reaching and they're funded in part by the Department of Mental Health and Addiction Services. Now, the only service I receive through them is psychiatry.</td>
<td>Both my previous therapist and my current psychiatrist were at the same agency. The site is a local mental health or behavioral health care service that reaches a lot of regions. I don't know if I would call them a Local Mental Health Authority, but they are that far reaching and they're funded in part by the Department of Mental Health and Addiction Services.</td>
</tr>
<tr>
<td>Negotiating the Place Between Client and Professional</td>
<td>Well, I would probably look for a therapist, um--at this point in my life I probably would look for a therapist outside of the agency. Um, mainly because, um, I might be looking for a job within the agency.</td>
<td>At this point in my life, I would probably look for a therapist outside of the agency mainly because I might be looking for a job within the agency.</td>
<td>At this point in my life, I would probably look for a therapist outside of the agency mainly because I might be looking for a job within the agency.</td>
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</table>
So--so, I don't know if I'll do that but--so, I have the option of finding a therapist within the agency. I'm not sure I need a therapist at this point.

Using Social Supports

Um, I know that there are times in my life when I do wish I had someone to talk to like that. But really, I was--probably under utilizing, um, the, um, outpatient therapy program--adult outpatient therapy. So--so, I--at this point I don't have one. I use my friends if I want to talk. I don't mean use but I mean consult friends if I need to talk to--about something. [So your social supports are able to feel some of those gaps?] My social--yeah, exactly.

Difficult Transitions

Yeah. [My therapist] Oh, god. She just left, like, I--I wanna say within the past--I always lose track of time, but probably, um, it's December, so she probably left October or November. It was a shock to me that she was leaving. I would say not just me, but we together as a collaborative, working team didn't have closure because I
was a transition for me that she was leaving and I didn't ha--we didn't have--I would say not just me, but we together as a working team, collaborative, um, didn't have closure because I missed an appointment that would've been the last appointment for her to see me. I haven't pursued what agency she went to and she wasn't at liberty to tell me where she was going. So, yeah, it was difficult. She was the third therapist I've seen at the agency. I saw her for maybe two years and prior to that I saw another therapist for a long time.

missed an appointment that would've been the last appointment for her to see me. I haven't pursued what agency she went to and she wasn't at liberty to tell me where she was going. So, yeah, it was difficult. She was the third therapist I've seen at the agency. I saw her for maybe two years and prior to that I saw another therapist for a long time.
<table>
<thead>
<tr>
<th>My First Therapist</th>
<th>The first therapist I had at the agency was the one I saw for the longest time. I started out seeing her in the mobile crisis unit, so she would come out to my house and we would meet outside in the community and things like that. At Dunkin Donuts or wherever. And then, when I recovered enough to not be in the mobile crisis unit, she transferred me to adult outpatient therapy and saw me there for a long time.</th>
<th>The first therapist I had at the agency was the one I saw for the longest time. I started out seeing her in the mobile crisis unit, so she would come out to my house and we would meet outside in the community and things like that. At Dunkin Donuts or wherever. And then, when I recovered enough to not be in the mobile crisis unit, she transferred me to adult outpatient therapy and saw me there for a long time.</th>
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<tr>
<td>Treatment Location</td>
<td>I've been in therapy for about 20 years, all at this agency.</td>
<td>I've been in therapy for about 20 years, all at this agency.</td>
</tr>
<tr>
<td>Lack of Therapeutic Connection</td>
<td>Yeah. I went--I went to see her mainly about--well, I started out--it started out that I called back--well, after, um, I'm not sure why I left my second therapist, e--or maybe she closed my case, but I was seeing the--the woman I was seeing</td>
<td>I'm not sure why I left my second therapist. Maybe she closed my case, or she changed her hours, or there was some reason. I can't remember. It could be a combination of reasons; we weren't working well together, or she changed the hours, or I wasn't engaged with her, not</td>
</tr>
</tbody>
</table>
in adult outpatient, I think she changed her hours or--d--there was some reason, I can't remember, it could be a combination of-just--we weren't working well together, um, or she too changed the hours or--or I wasn't going regularly or something, not engaged with her, not connecting. She called me psychotic once and I was like [chuckles] okay then. Um, but, um, so--so, but we had seen each other for a long time, it just--it w--I--we weren't connecting. So, I stopped going to therapy for a long time.

| My Last Therapist | and then I, um, started seeing, um, the third therapist and, um, it was originally to talk about weight issues and, you know, why I keep doing the same thing I k--keep doing, like doing things that are bad for me, um, in terms of, um, diet, nutrition, exercise, that kind of stuff. I just wanted to--to t--talk about the practical stuff that were impacting my self-esteem. So, originally it was that and then we were able to delve into some other issues. I'm in a care giving role in
<p>| And then I started seeing the third therapist. It was originally to talk about weight issues and, you know, why I keep doing the same things that are bad for me in terms of diet, nutrition, exercise, that kind of stuff. I just wanted to talk about the practical stuff that was impacting my self-esteem. So, originally it was that and then we were able to delve into some other issues. I'm in a care giving role in|
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<table>
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<tr>
<th>Therapeutic Connection</th>
<th>And we were able to connect on a much deeper level.</th>
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<th>And we were able to connect on a much deeper level.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Career Development</td>
<td>Also, um, I'm someone who was going through, um--I--I completed a masters program in social work, um, which--which is clinical social work and I haven't been able to find a job as a clinical social worker. So it was issues that we were talking about. So and wondering the difference between me and, you know--even though I work full time at a--a human rights agency and we work with peers who are in</td>
<td>Also, I was going through and completed a masters program in clinical social work and I haven't been able to find a job as a clinical social worker, even though I work full time at a human rights agency. I work with peers who are in recovery from substance abuse and mental health, so I was doing that kind of work and not really focusing on my social work career, even though I prepared to have a career in social work. So we talked about those issues.</td>
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recovery from substance abuse and mental health, so I was doing that kind of work and not--not really focused on my social work career even though I prepared to have a career in social work. Even as a--as a displaced worker. So we talked about those issues.

**Difficult Transitions**

So--s--so that's the kind of stuff we were doing in therapy, so when she told me she's leaving and she's going to another agency--and she's someone who has some things that, you know, I admire and we made a connection that was much deeper. Then she told me she's leaving and she's going to another agency. And she's someone who has some things that, you know, I admire and we made a connection that was much deeper. Then she told me she's leaving and she's going to another agency. And she's someone who has some things that, you know, I admire and we made a connection that was much deeper.

**Therapeutic Connection**

I would say that the first therapist I had and the third therapist I had there at that agency were able to connect around our profession. And--and--and--and so, um, you know I just felt more of a connection to, um, my first therapist who--first in the mobile crisis and, um, my third therapist. But, she left, so. I would say that the first therapist I began with in the mobile crisis unit and the third therapist I had at the agency, were able to connect around our profession. And so, you know, I just felt more of a connection to them. I would say that the first therapist I began with in the mobile crisis unit and the third therapist I had at the agency, were able to connect around our profession. And so, you know, I just felt more of a connection to them.
<table>
<thead>
<tr>
<th>Differences in Therapists</th>
<th>Oh, absolutely. Absolutely. There's a difference in approach in terms of their--um--the way they worked with clients and the way they transferred the knowledge that they had and listened.</th>
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</tr>
</thead>
<tbody>
<tr>
<td>My First Therapist</td>
<td>I think--I think--well, the first therapist was just a cool person. She was in the mobile crisis unit, she was just cool.</td>
<td>I think the first therapist was just a cool person.</td>
<td>I think the first therapist was just a cool person.</td>
</tr>
<tr>
<td>Therapeutic Connection</td>
<td>And, um, to be honest with you, I'm aware of what her sexual orientation was as well and we shared the same sexual orientation, although she was involved with a partner, um, and, um, they--after we stopped working together as client and therapist I--I, um, also learned o--before that--prior to that, I learned that her and her partner were married and--um--and they were having a baby together, so we were connecting around, um, that. It--th--that never entered into our work together, but it helped for her to have some understanding of who I am as--as a</td>
<td>And, to be honest with you, I'm aware of what her sexual orientation was as well and we shared the same sexual orientation, although she was involved with a partner. Prior to the end of us working together as client and therapist, I also learned that her and her partner were married and they were having a baby together. So, we connected around that. It never entered into our work together, but it helped for her to have some understanding of who I am as a woman and for me to know that she actually gets it, you know?</td>
<td></td>
</tr>
<tr>
<td>Being Supported in Professional Goals</td>
<td>[Laughs] So, i--w--we talked about s--and--and--and she was instrumental in supporting me when I first started at the agency I currently work for full time. I started as a volunteer and I--but--but she knew me when I started at that agency as a student, um, in, um, their advocacy education program.</td>
<td>And she was instrumental in supporting me when I first started at the agency I currently work for full time. I started as a volunteer, but she knew me when I started at the agency as a student in their advocacy education program.</td>
<td></td>
</tr>
<tr>
<td>Discovering the Behavioral Healthcare Community</td>
<td>So--so, before I even began working as a volunteer, I was a student enrolled in their advocacy education course and it was my introduction into the behavioral healthcare community in this state. ‘Cus I didn't know a behavioral healthcare community existed. Um, it was [sigh] probably five years into my diagnosis, my formal diagnosis, as--as somebody</td>
<td>So, before I even began working as a volunteer, I was a student enrolled in their advocacy education course and it was my introduction into the behavioral healthcare community in this state. I didn't know a behavioral healthcare community existed. It was probably five years into my diagnosis, my formal diagnosis, as somebody with a severe mental illness.</td>
<td></td>
</tr>
<tr>
<td>Topic</td>
<td>Description</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Being Supported in Professional Goals</td>
<td>So--so, she was really supportive of me. She attended my graduation from coursework and, you know, she came as a friend.</td>
<td>So, she was really supportive of me. She attended my graduation from coursework and, you know, she came as a friend.</td>
<td></td>
</tr>
<tr>
<td>Treatment that feels Human</td>
<td>Um, so, there was this--her--her whole professional style in interacting with clients were different. Um, mm mm. [Laughs] It was clear that it wasn't--wasn't equal, I mean it did feel more equal it j--I just felt--it felt more human and it felt more like she just got me as a person. It--I never felt like she was a friend, per say, but I didn't feel like she was someone who--because her role was to be with the patient in the community, so she came to the community. She would come to my house. She understood me and she was just someone who was easy to talk to. She was just--it was different. I don't--I</td>
<td>Her whole professional style in interacting with clients was different. It was clear that it wasn't equal; I mean it did feel more equal, it felt more human and it felt more like she just got me as a person. I never felt like she was a friend, per say, but her role was to be with the patient in the community, so she came to the community. She would come to my house. She understood me and she was just someone who was easy to talk to. She was just different. I don't know what to say, I hope I'm not getting her in trouble or anything like that as far as the way she worked, but she just kept it real. You know how you just have somebody that keeps it real with you. I dunno,</td>
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<tr>
<td>Process of Recovery</td>
<td>Yeah, just--I--I mean, she saw me, probably, through and worked through some of the--the darkest days. Like, early in recovery. I mean, I wasn't--I wouldn't even consider myself in recovery at the time she was seeing me. And--and my self esteem and a--all of that, um, my--I--I was paranoid, I--I had a very low self-esteem, um, just because I was coping with a mental health diagnosis in the first place and she saw me progress to the point where she said, &quot;I cannot keep you as a client anymore. You have to move on from here. You're not in crisis at this point.&quot; But they stay with you and they're with you until you reach that point, until you are able to use your community supports, and family,</td>
<td>she was just a cool therapist.</td>
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</table>
not in crisis at this point." And so that's how--but they stay with you and they're with you until you reach that point, until you are able to use your community supports and family and friends and--and stuff. But prior to that, I wasn't able to.

| Therapeutic Connection | Yeah, yeah. So--so, that's the different with connecting with someone who was like that. And also, I have to say, that she wore, um, I mean, her whole style and appearance was just different. Like--like a friend of mine, like the friends I have, you know, who dress a certain way and their way of being in the world is different. And so--and there are some people who--who don't--who, like me, like, have a standoffish attitude toward people. But, no, um, I--I couldn't do a--just the way she carried herself made it--made it comfortable. Made me feel comfortable. | So, that's the difference with connecting with someone who was like that. And also, I have to say, her whole style and appearance was just different. Like a friend of mine, like the friends I have, you know, who dress a certain way and their way of being in the world is different. And there are some people who, like me, have a standoffish attitude toward people. But, just the way she carried herself made it comfortable, made me feel comfortable. |

<p>| Changes in Mental Health Care | Yeah. Well, I would say that, um, certainly h--if the past is the way I just described it, that's-- | That was 2004, 2005, when I saw the first therapist. But, so, prior to that is a time when the mental health care |</p>
<table>
<thead>
<tr>
<th>Treatment that feels Human</th>
<th>if it weren't for an occupational therapist</th>
<th>If it weren't for an occupational therapist</th>
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<td>th--that was, um, probably--when was that? That was 2004, 2005, when--when I saw the first therapist. But, um, [pause] so, prior to that is a--is a time when the--the mental health care system left a lot to be desired. Individuals in the mental health care [pause] were kinder.</td>
<td>system left a lot to be desired. Individuals in mental health care are kinder.</td>
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| Traumatic Treatment | I've received mental health care in two states. And so from, let's say, 1999 to 2004, I was living in another state and I received poor treatment in a hospital there. I was restrained for not being harmful or violent, but I think by and large because of the way I looked. I was placed in four point restraints because I patted a patient on the head and you weren't supposed to go into patient rooms, but I didn't know what I was doing. But I know I wasn't violent when I was abused like that. So, I received traumatic treatment at that hospital | I've received traumatic treatment at that hospital |
was doing. But, I know I wasn't violent when I was abused like that. So, I received traumatic treatment at that hospital and, um,

<table>
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<tr>
<th>Being Forced to take Medication</th>
<th>and was forced to take medication which I later learned you cannot force someone, um, to take medication unless you deem them to be a danger to themselves or--or other people and I wasn't a danger.</th>
<th>and was forced to take medication, which I later learned you cannot do unless you deem someone to be a danger to themselves or other people and I wasn't a danger.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Traumatic Treatment</td>
<td>Um, so [pause] I was really traumatized by the mental health care system, um, and--and multiple people, um, placed me on a gurney in four point restraints and, um, I was naked.</td>
<td>So, I was really traumatized by the mental health care system. Multiple people placed me on a gurney in four point restraints and I was naked.</td>
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<tr>
<td>Anger</td>
<td>So, um, so there--there's some--I feel some kind of way about that kind of treatment</td>
<td>So, I feel some kind of way about that kind of treatment</td>
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<tr>
<td>Being Forced to take Medication</td>
<td>and, um, how I probably would not have been let out of that facility unless I agreed to, um, take medication. And that was the case. Because, prior to that, I refused to take medication and so the interdisciplinary team would come and, um, try to talk to me about taking it. &quot;Are you gonna take the medication? Are you gonna take&quot;-- &quot;No, I'm not gonna take the medication. Why do I need medication?&quot; That kind of conversation. And I thought, um, at the time, that I was being reasonable by refusing to take medication. There was no good reason for me to take medication. But I quickly learned in that facility that-- that--that went on for about a week there, I was there for two weeks, it went on for about a week, until it dawned on me, and how I probably would not have been let out of that facility unless I agreed to take medication. And that was the case. Because, prior to that, I refused to take medication and so the interdisciplinary team would come and try to talk to me about taking it. &quot;Are you gonna take the medication?&quot; &quot;No, I'm not gonna take the medication. Why do I need medication?&quot; That kind of conversation. And I thought, at the time, that I was being reasonable by refusing to take medication. There was no good reason for me to take medication. But I quickly learned in that facility. I was there for two weeks, it went on for about a week, until it dawned on me that, you know, they're not gonna let me out.</td>
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<tr>
<td>Deciding to take Medication</td>
<td>um--I--th--I was given Haldol when I was restrained and, um, the next day I actually did feel better, um, calmer, um, and--and, um, one of my friends came to visit me and I said, &quot;What,&quot; you know, &quot;what happened?&quot; Or &quot;Why am I feeling so much calmer?&quot; Or this that and the other thing. And he said that, um, he said, &quot;You know, you had--you were medicated.&quot; And I said, &quot;Oh, is that the impact of medication?&quot; And he said, &quot;Yes.&quot; I said, &quot;Maybe I should take it to get out.&quot;</td>
<td>I was given Haldol when I was restrained and the next day I actually did feel better, calmer. And one of my friends came to visit me and I said, &quot;What happened?&quot; Or &quot;Why am I feeling so much calmer?&quot; Or this, that, and the other thing. And he said, &quot;You were medicated.&quot; And I said, &quot;Oh, is that the impact of medication?&quot; And he said, &quot;Yes.&quot; I said, &quot;Maybe I should take it to get out.&quot;</td>
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<tr>
<td>A Lack of Rights</td>
<td>You know, they're not gonna let me out-it wasn't, like, you know, the stuff I learned at A.U. about patients' rights being posted and, um--um, you know, having to know where, um, wh--that you have the right to refuse and I thought I had been committed to this hospital and later realized that I had signed paperwork so it was voluntary the whole time, but, um, I think they were gonna commit me,</td>
<td>It wasn't like the stuff I learned later about patients' rights being posted and having to know that you have the right to refuse. I thought I had been committed to this hospital and later realized that I had signed paperwork so it was voluntary the whole time, but I think they were gonna commit me. So, it was just a really bad scene.</td>
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<tr>
<td>Anger</td>
<td>I'm trying to talk about it really detached [chuckles] but I'm getting angry at this point, but, so, it's really kinda pathetic. Yeah, [laughs] yeah.</td>
<td>I'm trying to talk about it really detached, but I'm getting angry at this point, so it's really kinda pathetic.</td>
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<tr>
<td>Learning about Rights</td>
<td>You know, i--what happened to me and what I later learned when I moved back to this state about the rights--patients bill of rights is, you know, something that was obliterated--my rights were obliterated, no one told me, I didn't know--I really was shocked, um, that, um, that I was even admitted to the hospital in the first place.</td>
<td>What happened to me and what I later learned when I moved back to this state about the patients' bill of rights is something that was obliterated. My rights were obliterated. No one told me, I didn't know. I really was shocked that I was even admitted to the hospital in the first place.</td>
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<tr>
<td>Agreeing to Seek Treatment</td>
<td>I agreed, um, to go and be evaluated, um, because of a--a situation that occurred between me and a girlfriend and,</td>
<td>I agreed to go and be evaluated because of a situation that occurred between me and a girlfriend.</td>
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<tr>
<td>The Price of Freedom</td>
<td>um--so going through that experience I learned that there's a certain way a patient has to talk in order to be heard and in order to have what we desire to have. And so what I did was agree to take the medicine so</td>
<td>So, going through that experience I learned that there's a certain way a patient has to talk in order to be heard and in order to have what we desire to have. And so what I did was agree to take the medicine so that they would let me out</td>
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<tr>
<td>Family Involvement in Treatment</td>
<td>So, I also had family members that weren't advised of my rights or--or their rights as</td>
<td>I also had family member that weren't advised of my rights or of their rights as</td>
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that they would let me out of that facility at some point and so--so the next week I started a medication regimen and was, um, discharged on my birthday, um, and that was a week later. So, it was in February of 1999, um, and, um, they let me out. And then I went and I saw a doctor and learned quickly, you know, when you go through the many mental status exams, um, that there are certain ways you have to answer those questions and there's certain ways you have to look in order to get over--in order to--for the--the providers to view you a certain way. Yeah for--yeah and--and--and all the talk was about being med compliant, being treatment compliant and it really is pathetic, but that's what I went through in order to--to have freedom and the freedom came with a price also.
family members. I, you know, I had people who would just say, "Take your medicine, take your medicine, take your medicine" in my family, so the boundaries between them and the issues in--in terms of the relationship healing, is taking some time because I still never forget, although I forgave them for their role, because they had a lack of information.

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<th>What Propels me Forward</th>
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<td>But, I went through something and--and I hope to never go through it again and it--it is probably what propels me forward to--to not have those times return for anybody I know. And, um, it is what, um, led me to want to be a part of an organization here so that we end restraint and seclusion, because of my experiences in restraints.</td>
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<tr>
<td>But, I went through something and I hope to never go through it again. It is probably what propels me forward, to not have those times return for anybody I know. My experiences in restraints led me to want to be a part of an organization here that works to end restrained and seclusion.</td>
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<th>Traumatic Treatment</th>
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<td>And I was restrained after; I was actually restrained in this state, in a hospital here, as well during that time period between 1999 and 2004 probably.</td>
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<td>Changes in Mental Health Care</td>
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<tr>
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<td>Being Forced to take Medication</td>
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The only reason I continued to take medication then and took it then and continue to take it is because I have a family and specifically three family members in particular, who believe in Western medication, in pills, and believe--and didn't believe that I had a right to choose what kind of treatment I accept, you know. They didn't believe that the decision to take meds or not take meds is between me and my service providers. Evidently, 'cus i--that would be the only reason that they would encourage me to do that. I happen to believe that it's between me and my service providers. So--[sigh] so, that's pathetic in and of itself, to me, still.
| Freeing Yourself Within | and [laughs]--and also the way the behavioral health care system at the hospital was--was pathetic, because they restrained me, um, and the only thing I could tell you is thank god I had practice, um, in my undergraduate, um, life [pause] like transcendental meditation or yoga, because the only way to deal with four point or two point restraint is to go inward, to try to calm yourself because what happens is I was like confronted with "take your medication" and my blood pressure went through the roof and I'm in these restraints and you can't move and you can't scratch or whatever, um, anything. You--you--you can only free yourself within and so that's what I did in order to get through the experience until they removed them. | Also, the way the behavioral health care system at the hospital was was pathetic because they restrained me. And the only thing I could tell you is thank god I had practice in my undergraduate life with transcendental meditation and yoga, because the only way to deal with four point or two point restraint is to go inward, to try to calm yourself. Because what happened is I was confronted with "take your medication" and my blood pressure went through the roof and I'm in these restraints and you can't move and you can't scratch or whatever, you can't do anything. You can only free yourself within and so that's what I did in order to get through the experience until they removed the restraints. |
| Dehumanizing Treatment | And I'm not saying that I'm perfect, but I'm saying no human being deserves that. It's just--no human being deserves that, so. So, um, that is far | And I'm not saying that I'm perfect, but I'm saying no human being deserves that. No human being deserves that. That is far from recovery |
from recovery oriented, I think. [laughs] Yes, so, I mean, the way we treat--treated people, yeah. So, that experience lives with me still, um, I try to talk about it in a detached way, um, until I meet other people who have gone through the experience and I say, "I know what it's like and I know how it makes you feel." And you don't feel like you have the power to do anything, not change the system, not do anything. So, [pause] yeah. [groan] Gosh. [pause] Well... Well, I was--how it makes you feel? Um, [pause] certainly dehumanized.

| What Propels me Forward | Um, [pause] hm. [pause] I just, you know, I think it strengthens my resolve to never be a person that makes other people feel that way. So, I mean, that's--I try to look at the bright side of what going through an experience like that [pause] causes. But--I've written papers about it too--um, that, um--it traumatizes you. And I think it strengthens my resolve to never be a person that makes other people feel that way. I try to look at the bright side of what going through an experience like that does. I've written papers about it too, about the way it traumatizes you. I have to relate to it from a spiritual perspective. |
it traumatizes you in a way that--like I said, the only [pause]--like, I have to relate to it, excuse me, from a spiritual perspective and I think, um,

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<tr>
<th>Anger</th>
<th>[pause] f--I'm angry that that happened to me. I continue to be angry that that happened to me. And--but I know that I'm not alone, so I'm angry that it's happened to anybody.</th>
<th>I'm angry that that happened to me. I continue to be angry that that happened to me. But, I know that I'm not alone, so I'm angry that it's happened to anybody.</th>
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<tr>
<td>Dehumanizing Treatment</td>
<td>And, because I--it's just not [pause]--I like to think I'm a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. A--I think none of us--there--there's not a single solitary soul that I feel deserves to be placed in four-point restraint.</td>
<td>I like to think I'm a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. I think none of us, there's not a single solitary soul, that I feel deserves to be placed in four-point restraint.</td>
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<tr>
<td>Dehumanizing Treatment</td>
<td>It is the most dehumanizing thing and if we call behavioral health care &quot;care,&quot; then where is it? When it comes to that type of treatment: isolation, restraints, whether they're two point, four point, wrapping people in chains or, you know, where—where is it? That is the—if you wanna make someone feel dehumanized like a dog or I mean I don't even treat animals like that. That's [laughs] you—we—the Humane Society exists to stop that kind of treatment but where is the human Humane Society? And when it comes to psych treatment—and we call it treatment, how do we call it treatment?</td>
<td>It is the most dehumanizing thing and if we call behavioral health care &quot;care,&quot; then where is it? When it comes to that type of treatment: isolation, restraints, whether they're two point, four point, wrapping people in chains, where is it? If you want to make someone feel dehumanized like a dog, I mean, we don't even treat animals like that. The Humane Society exists to stop that kind of treatment, but where is the human Humane Society? And when it comes to psych treatment, and we call it treatment, how do we call it treatment?</td>
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<tr>
<td>Traumatic Treatment</td>
<td>So, the fact that that's our history sucks. I just—I don't have the words. I just—I d—I just [laughs]. Just, yeah. And—and we expect people to emerge from that unscathed. I think we do, right?</td>
<td>So, the fact that that's our history sucks. I just don't have the words. And we expect people to emerge from that unscathed. I think we do, right?</td>
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<tr>
<td>Medical/Physical Restraints</td>
<td>Take your medicine. Um, so, whether it's chemical restraints</td>
<td>&quot;Take your medicine.&quot; So, whether it's chemical restraints or</td>
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<tr>
<td>What Propels me Forward</td>
<td>There has to be a better way. And I think we haven't found it yet.</td>
<td>There has to be a better way. And I think we haven't found it yet.</td>
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<tr>
<td>Changes in Mental Health Care</td>
<td>We--I mean, one state hospital has increased restraints--restraint hours, people have died from them.</td>
<td>I mean, one state hospital has increased restraint hours. People have died from restraint.</td>
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<tr>
<td>Anger</td>
<td>Um, yeah. I'm angry still. I just--I'm trying to contain myself. My friend says, &quot;You're so calm, you're so calm,&quot; I'm like, &quot;inside&quot;--I know, because--no, I know looking like me I have to say--I have to say, I dunno,</td>
<td>I'm angry still. I'm trying to contain myself. My friend says, &quot;You're so calm, you're so calm.&quot; I'm like, &quot;On the inside I'm not.&quot; But I know looking like me, I have to seem calm.</td>
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<tr>
<td>Treatment Based on Appearance</td>
<td>because at the time my hair was in locks, you know, I might have--I looked bigger, I--I weighed more, um, I--I'm not saying there's a difference, but I'm saying there's a difference in how you're treated and I--I would say I was restrained by at least seven or eight people, most of them were men,</td>
<td>At the time I was restrained, my hair was in locks, you know, I might have looked bigger, I weighed more, I'm not saying there's a difference, but I'm saying there's a difference in how you're treated. And I would say I was restrained by at least seven or eight people, most of them were men.</td>
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<td>Dehumanizing Treatment</td>
<td>and the way that--like I--I wanna know this: how do individual people allow</td>
<td>I wanna know this: how do individual people allow themselves to treat</td>
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<tr>
<td>Dehumanizing Treatment</td>
<td>um. I--I--I can't think of a kind nurse, I can't</td>
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<tr>
<td>Desires not being Respected</td>
<td>the doctor, she wanted me to take medicine and so that was her goal, for me to take medicine in order to get out and not say--I mean, she didn't say, &quot;Okay, well, let's look at</td>
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<tr>
<td>Treatment that feels Human</td>
<td>And if it wasn't for the occupational therapist on that unit, I would really have lost faith in humanity. Yeah. Not during that particular time, but it was--it was the other patients in the unit and the occupational therapist that actually [pause] helped me with washing my clothes after I agreed to take their medication to get out. So, she actually treated me like I was a human being, regardless of her job, you know. It was like she went above and beyond to be kind. She was someone who [pause] [laughs]--maybe she didn't like the treatment, the way they treated patients on that unit herself,</td>
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<tr>
<td>Desires not being Respected</td>
<td>The doctor at the hospital, she wanted me to take medicine and so that was her goal, for me to take medicine in order to get out. I mean, she didn't say, &quot;Okay, well, let's look at</td>
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other human beings like that, policy or no policy? I just don't know. I just don't get it.
some alternative ways for you to heal," she didn't say that. For her, medication was the . . . The answer, yeah. And--and--and talk about cultural competency and respecting somebody's desires not to take a pill, not to take a chemical, and--and so some alternative ways for you to heal." For her, medication was the answer. And talk about cultural competency and respecting somebody's desires not to take a pill, not to take a chemical!

**Family Involvement in Treatment**

and even members of my family didn't get it, and so I knew [laughs] I would be stuck in that facility if I didn't adhere to their wishes.

Even members of my family didn't get it and so I knew I would be stuck in that facility if I didn't adhere to their wishes.

**Treatment Location**

Mm mm. Prior to--prior to that I didn't have a--well, here--before I left, 'cus I have--this was--this hospitalization occurred maybe a week after I moved to a different state. So--a different city--and

The hospitalization occurred maybe a week after I moved to a different state.

**Agreeing to Seek Treatment**

so--so prior to [sigh][pause]--prior to that, I was asked to take a leave of absence from work. I was working and I was asked to take a leave of absence, because I snapped at one of our students who asked me something personal and probably my boss was like, "You need to take care of yourself. You need to

Prior to that, I was asked to take a leave of absence from work because I snapped at one of our students who asked me something personal. Probably, my boss was like, "You need to take care of yourself. You need to get some rest and see somebody." She was of the mindset that I needed to do that and I agreed with her,
get some rest--see somebody." And--and so she--she was of the mindset that I did and I agreed with her,

| Seeking Treatment for the Voices | so I went and I finally said--um--'cus I'm a voice hearer, so I finally said to somebody, "I hear voices." And, um--a psychiatrist this time, prior to that I had gone to a psychiatric nurse and, you know--so, I, um, I went and he immediately said, "Well, how long have you been hearing voices? What is the content?" You know, the typical questions you get. I answered his questions and he sent me away with a prescription for Risperdal. I had previously gone to see a psychiatric nurse. | so I went to see a psychiatrist. I'm a voice hearer, so finally said to somebody, "I hear voices." He immediately said, "Well, how long have you been hearing voices? What is the content?" You know, the typical questions you get. I answered his questions and he sent me away with a prescription for Risperdal. |
| Career Development | After a while, I went back to work, 'cus I could still keep my job. | After a while, I went back to work, 'cus I could still keep my job. |
| Similarities in Mental Health Care | and, um, shortly after that I decided to move, which was a mistake, obviously, in my life, you know, hindsight is 20-20, moving away from, um, this state was a mistake. So, I moved and, um, ended up in the hospital with that treatment. So--so, that | Shortly after that I decided to move, which was a mistake, obviously, in my life. You know, hindsight is 20-20. So, I moved and ended up in the hospital where I was restrained. So, that was huge. But it doesn't matter. I was still restrained in the |
was huge, but it doesn't matter, it still happened here as well after I moved back [laughs], you know, that I was restrained again

| Hospital here as well, after I moved back. |

| Unwarranted Treatment | And when I say that I didn't do anything to warrant those restraints, I mean that. Who does anything to warrant that? I mean, I understand. I wasn't, like, escalated. People restrained me in order to get me to take medication or because, like I said, I had gone into a patient's room in a distressed moment. I was having an experience where I was having a dream, it wasn't a nightmare, it was a dream, where I felt like my brother was talking to me and I went into the patient's room and I rubbed his head and I called him my brother’s name and that was it. But evidently, I didn't have on any clothes at the time and had been going through something. But I wasn't a danger to the patient and I didn't do anything that was violent. They asked me to go back to my room and I was, like, |

| and--and when I say that I didn't do anything to warrant those restraints, I mean that. That is not something--I--I--I--who does anything to warrant that, I mean I understand--I wasn't like, escalated--people wanted me--people restrained me in order to get me to take medication or because, like I said, I had gone into a patient's room in a--in--in--in a distressed moment, I walked into his room--I was having an experience where I felt like--this was pre, uh, reuniting with my son--I'm awful--also a birth mother--and, um, I was having a dream, I think, I had a dream--it wasn't--it wasn't a nightmare, it was a dream, where I felt like my brother was talking to me and I went into the patient's room and I rubbed his head and I called him my brother's name and that was it, but evidently I didn't |
I have on any clothes at the time and, um, had been going through something, but I wasn't a danger to the patient and I didn't do anything that was violent and that was why, um, I had--they asked me to go back to my room and I was like still probably in a malaise or something and, uh, didn't w-- want them to tell me to go back to my room or something, but it didn't warrant eight people throwing me down on a gurney and restraining me for a night or whatever. Yeah, it was crazy.

Learning about Rights

So--so--so that was my pre-recovery oriented [laughs] system and pre-knowing about my rights. That kind of thing could never happen to me again, I know they say never say never, but, um, yeah

So that was my experience of the pre-recovery oriented system and pre my knowing about my rights. That kind of thing could never happen to me again. I know they say never say never.

What Propels me Forward

--make sure it doesn't happen to anybody else. So, yeah.

We need to work to make sure it doesn't happen to anybody else.

Treatment that feels Human

Um, I think providers now--the provider that I have--the psychiatrist that I have now listens more, um, I--I think, um, he's learned something from, not

The psychiatrist that I have now listens more. I think he's learned something from, not just me as his patient, but his other patients as well. He's learned to listen
<table>
<thead>
<tr>
<th>Keeping Experiences Private</th>
<th>I haven't shared that part of my history with anybody, so--so, um, except a few select people, so it's not public knowledge. Yeah, I'm gonna share it with you because you're doing a dissertation [laughs] on what the system was like and that's how it was for me, um, I haven't shared that part of my treatment history with anybody except a few select people, so it's not public knowledge. I'm gonna share it with you because you're doing a dissertation on what the system was like and that's how it was for me.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in Mental Health Care</td>
<td>but he--he, um, said that he has patients with, um, tardive dyskinesia so bad that he can't continue to prescribe anti-psychotic medications to them. And so he's working with me in reducing medication, the anti-psychotic,' The psychiatrist said that he has patients with tardive dyskinesia so bad that he can't continue to prescribe anti-psychotic medications to them. And so he's working with me in reducing the anti-psychotic medications.</td>
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<tr>
<td>Deciding to take Medication</td>
<td>cus one--one of the things that happened is while I never desired to be on any</td>
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<tr>
<td>Being Forced to take Medication</td>
<td>psych meds in the first place and, um, I've taken a lot of them over the course of that time--from that time--from 1999 to the present and I've taken a lot of them, some of them I had adverse side effects too and e--everything.</td>
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<td></td>
<td>but it has to be not only, um, to satisfy my family and hate myself every time I take them, but also it was to--to get out of the facilities in the first place and then to satisfy my family, who, like I said, believed that you should take medicine if you have a mental illness and then it was my own doing, like I take full responsibility for continuing to take it even though I feel some kind of way about, um, taking it and its effectiveness. It has never stopped the voices that I hear and, um, I don't take anti-anxiety medication.</td>
</tr>
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</table>
The Emotional Impact of the Voices

I used to take that 'cus I experienced anxiety, um, social phobia, I couldn't be in public--in the public period. I couldn't go to grocery stores, I couldn't, um-um, do events. I--I--um--I was teaching prior to that in front of groups of people, that's my role now in the job, um, teaching, um, and being--I couldn't be in public places, I couldn't facilitate support groups where there were people talking because of the voices and--and my experience with voices, not because of the voices, but because of my experience with, um, the voices and how they make me cringe sometimes and feel out of sorts. I couldn't do it. But I've recovered and now I can do it.

Impact of Medication

i--he--so he said he has tardive dyskinesia--he has patients with tardive dyskinesia so bad--and even though he checks me or whatever--he listens to me

The psychiatrist said he has patients with bad tardive dyskinesia. He checks me to make sure I don't develop it.
<table>
<thead>
<tr>
<th>Treatment that feels Human</th>
<th>it's a 20-minute appointment, but he listens to me and he knows that I facilitate a Hearing Voices group for people to talk about the experience of voice hearing and all of that kind of stuff.</th>
<th>It's a 20-minute appointment, but he listens to me and he knows that I facilitate a Hearing Voices group for people to talk about the experience of voice hearing and all of that kind of stuff.</th>
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</thead>
<tbody>
<tr>
<td>Growth as a Professional and Advocate</td>
<td>I’m involved with the Hearing Voices Network and we brought this to the State through, um, someone who worked for the Department of Mental Health and Addiction Services and, um, we have 14 groups now, we started with six and so there's, um, [pause]</td>
<td>I'm involved with the Hearing Voices Network and we brought this to the state through someone who worked for the Department of Mental Health and Addiction Services. We started out with six groups and now we have 14 groups.</td>
</tr>
<tr>
<td>Changes in Mental Health Care</td>
<td>we have a voice and I have a voice today that I didn't feel I was being heard by service providers. I still think there's some service providers who don't hear me when I speak, who don't recognize that we do have choices, as people with a mental health condition we have choice--ultimately the choice should lie within us,</td>
<td>So, we have a voice and I have a voice today that I didn't feel was being heard by service providers before. I still think there's some service providers who don't hear me when I speak, who don't recognize that we do have choices. As people with a mental health condition we have a choice. Ultimately the choice should lie within us.</td>
</tr>
<tr>
<td>Family Involvement in Treatment</td>
<td>it should be between me and my service provider, not other people who think they know what's best for</td>
<td>The choice should be between me and my service provider, not other people who</td>
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<tr>
<td>Emotion</td>
<td>Statement</td>
<td>Thoughts about it</td>
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<tr>
<td>Anger</td>
<td>And so, I have an attitude about it, I know you could probably hear it and some anger [laughs], you know--anger about it, uh--so--so</td>
<td>I have an attitude and some about it, I know you could probably hear that.</td>
</tr>
<tr>
<td>Treatment that feels Human</td>
<td>but I--I feel like my psychiatrist, at least, is getting it and he understands and he's--he's not certain what the outcome will be with me, but at least he's willing to work with me and say, &quot;Okay.&quot; [Deep breath] Yeah. The psychiatrist I had out of state, he's been the-p--probably the--I--I had another one in a partial hospital program that was different from him, but I've been with him since 2006, maybe 2005 or something--he's been my psychiatrist for all this time. And so he's seen my growth and development as a human being and as a professional and I think that has probably made a difference for him. You can't be in behavioral health in this state without knowing that recovery is possible, I don't think. Is it possible to not know that? It's real for people.</td>
<td>But, I feel like my psychiatrist, at least, is getting it and he understands. He's not certain what the outcome will be with me, but at least he's willing to work with me and say, &quot;Okay.&quot; I've seen this psychiatrist since 2006, maybe 2005 or something, he's been my psychiatrist for all this time. And so he's seen my growth and development as a human being and as a professional and I think that has probably made a difference for him. You can't be in behavioral health in this state without knowing that recovery is possible, I don't think. Is it possible to not know that? It's real for people.</td>
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<th>Involvement in Treatment Decisions</th>
<th>and there's some alternatives that we need to be about integrative medicine, holistic healing, um, offering people choice. People want to be offered choices and not--people want to be a part of their treatment plans.</th>
<th>There's some alternatives that we need. We need to be about integrative medicine, holistic healing, and offering people choice. People want to be offered choices and be a part of their treatment plans.</th>
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<tbody>
<tr>
<td>We Still Have a Long Way to Go</td>
<td>So, I think we have a long way to go in terms of, um, helping people because I still think the difference--you asked me about some of the treatment providers and I know, um, we have a little time, but, um--that--um--I think the third therapist that I had still--and probably m--m--my lack of insistence that I be a part of the treatment planning. I think that still is an area that needs to be addressed. We have a document that Yale is responsible for putting together, called Getting in the Driver's Seat of Your Treatment Plan. That document is still not being utilized everywhere. So we have a long way to go in terms of helping, I'm going to call them patients, but helping</td>
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<td>So, I think we have a long way to go in terms of helping people. Even with the third therapist I had, an old treatment plan was still being used, just to get you to sign it so that they could get funding. Probably is was partly due to my lack of insistence that I be a part of the treatment planning. I think that still is an area that needs to be addressed. We have a document that Yale is responsible for putting together, called Getting in the Driver's Seat of Your Treatment Plan. That document is still not being utilized everywhere. So we have a long way to go in terms of helping, I'm going to call them patients, but helping</td>
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Getting in the Driver's Seat of Your Treatment Plan. That still—that document is not being utilized everywhere and so it-it—it's still—uh—we have a long way to go in terms of helping [pause], I'm going to call them patients, but helping people get in the driver's seat of their treatment plan with agencies because I—even—even me, knowing and teaching it, I still go to a facility and on the most recent treatment plan I signed, I really just signed it. We didn't have a conversation—the first—about what are my goals, although she knows, I want to get a job as a social worker—that's not in there.

Client Involvement in Change

Yeah. I think—I think otherwise there's a risk that it will continue at the status quo. It will con--business as usual will continue, if we don't, as clients, insist that we're a part of it, that the conversation takes pl--like, it's almost like insisting that, "Are you gonna ask me?" And--and we can do it nicely, we

If we don't, as clients, insist that we're a part of it and that the conversation takes place, I think there's a risk that it will continue at the status quo. It's almost like we have to insist on saying, "Are you gonna ask me?" And we can do it nicely, we don't have to be hostile like I am. We could do it like, "Are
You don't have to be hostile like I am. We could [laughs]--we could do it like, "Are you gonna ask me" [laughs] "what my goals are in different areas of my life? Do I have financial goals, do I wanna own a house or get a different apartment? Do I want to have social relationships that are rewarding?" You know, "Are--are you gonna ask me those questions?" And I think we have to insist, as clients, that the qu--give them the questions when they don't have it.

Changes Still Needed

But, I also think some training has to take place on the part of agencies' staff development. Like they should--they should know that that document exists, especially some of them coming out of, um, programs--therapist--social work programs, they should insist that, um, they should know about those documents and other documents. They should know about WRAP, they should know about--um--you know, because a lot of people in this state you gonna ask me what my goals are in different areas of my life? Do I have financial goals, do I wanna own a house or get a different apartment? Do I want to have social relationships that are rewarding?" You know? "Are you gonna ask me those questions?" And I think we have to insist, as clients. We have to give them the questions when they don't have them.

But, I also think some training has to take place on the part of agencies' staff development. Like, they should know that that document exists. Especially the staff coming out of social work programs, they should know about those documents and other documents like that. They should know about WRAP, because a lot of people in this state who have WRAP and if the clinicians don't know that there's such a thing, it can't be put to use. I mean, I don't
| Changes in Mental Health Care | Oh, it stands for Wellness Recovery Action Plan and Mary Ellen Copeland--um--Mary Ellen Copeland developed it and SAMSA uses it--there's no such thing as SAMSA, but the Health and Human Services Department, uh, uses it, um. You know, it's called recovery planning or planning recovery, recovery action planning or something. It's been translated across, um, the globe and, um, people use that to help them manage their symptoms and to take action when they need to address certain areas. | It stands for Wellness Recovery Action Plan and Mary Ellen Copeland developed it and SAMSA uses it. There's no such thing as SAMSA, but the Health and Human Services Department uses it. You know it's called recovery planning or planning recovery, recovery action planning, or something. It's been translated across the globe and people use that to help them manage their symptoms and to take action when they need to address certain areas. |
| Involvement in Treatment Decisions | It is possible to use programs like a Wellness Recovery Action Plan and--as well as holistic healing and manage our symptoms | I still take a little medication, but it is possible to use programs like a WRAP as well as holistic healing and manage our symptoms |
without medication. I believe. This is just me. But if another person believes that they need a little medication--and I still take medication, but if another person need--they need a little medication and they need those other things, then a therapist should support them in continuing to do that.

Client Involvement in Change

and that's the kind of education . . . Well, I found myself in a position as a client of sharing information with my therapist that they don't know. And not only that, as a spouse of a woman who is in private practice, sharing information with her that she then shares it with her therapist that they don't know in private practice. I find myself in that role all the time and I--I was like, "Why don't they pay me to te" [laughs], you know? Yeah, I know [laughs]. It--it's so funny. I j--I ju--so, And that's the kind of education people should be getting. Well, I've found myself in a position as a client, sharing information with my therapists that they don't know. And not only that, as a spouse of a woman who is in private practice, sharing information with her that she then shares with her therapist that they don't know. I find myself in that role all the time and I'm like, "Why don't they pay me?," you know. It's so funny.

Mutual Growth

but really the benefit is that my therapists treat me better as a result and--and I also learn from them, I don't--'cus I don't know everything, so I But really, the benefit of sharing information is that my therapists treat me better as a result and I also learn from them, 'cus I don't know
also learn from them. Like, that's why the third one, when she left, I experienced that loss greatly because, you know, sh--you know, I was learning a lot from her as well, so--so.  

| Changes Still Needed | But there's pockets that people need training, they need professional development. And that isn't all about they need advanced learning in--in those areas and--and sometimes it's unfortunate when the schools don't prepare them. Like, um, I went to this agency as an intern and the director of the agency said, "You know, the school that I went to is still using the same curriculum 20 years ago." And, you know, while I found it rigorous it--and it was kind of an insult to hear her say that [laughs], I was like, "Wait a minute," 'cus I learned a lot in that program, you know, and, um, the teachers weren't outdated at all. But I know that, but--but it's still the same thing about what they want professionals coming out of masters social work programs to know and be able to do. And that's not the | everything. Like, that's why when the third therapist left, I experienced that loss greatly, because, you know, I was learning a lot from her as well. |
work programs to know and be able to do. And that's not the only game in town in terms of where our clinicians are trained and what kind of schooling they have before they . . . only game in town in terms of where our clinicians are trained and what kind of school they have.

<table>
<thead>
<tr>
<th>Treatment Location</th>
<th>Um, I've been at the same agency in this state since 2004,</th>
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<tbody>
<tr>
<td>Differences in Therapists</td>
<td>so, um, [sniff] I think the biggest thing that, um, my--I--I think my therapists view me as capable and competent and they didn't always.</td>
<td>I think my therapists view me as capable and competent, but they didn't always.</td>
</tr>
<tr>
<td>Lack of Therapeutic Connection</td>
<td>Like I said, like the one that I had prior to the third one--the second one, she called my psychotic. And she did--and--and I thought, &quot;Why would you call someone that label?&quot; You know. I mean, I can't remember the whole context to give you an idea, but I just think that's a travesty. Especially when you know that uh--I--I can't figure out what happened--I can't make excuses for her. I just think that I--I--I</td>
<td>Like I said, the second therapist I saw, she called me psychotic. And I though, &quot;Why would you call someone that label?&quot; You know, I mean, I can't remember the whole context to give you an idea, but I just think that's a travesty. I can't figure out what happened, I can't make excuses for her. We were having a conversation and she was like, &quot;Yeah, but you're psychotic.&quot; And she was trying to</td>
</tr>
<tr>
<td>Medication Being Central to Treatment</td>
<td>maybe it was a conversation about medication, again. It's always been u--f--for them, it's always been about &quot;Y--are you taking your meds&quot; or, you know--even--that wasn't her role, her role was to do talk therapy.</td>
<td>maybe it was a conversation about medication again. For them, it's always been about &quot;Are you taking your meds?&quot; That wasn't her role, her role was to do talk therapy.</td>
</tr>
<tr>
<td>Dehumanizing Treatment</td>
<td>So, I think . . . Yeah. It's--it's like using stigmatizing words--I can't think ever of a reason to be engaged with a client over a-- a--to have a conversation with a client, ever, that I would call them a label that is in their file. I wouldn't. For what reason--can you? [Laughs] Right. I would refer t--to clients the way that-- in fact,</td>
<td>It's using a stigmatizing word. I can't think there's every a reason to be engaged with a client, having a conversation, ever, when I would call them a label that is in their file. I wouldn't. For what reason? Can you? I would refer to clients the way that they wanted to be referred.</td>
</tr>
<tr>
<td>Disrespecting Clients</td>
<td>I--I was in a conversation with someone--even a conversation with one of my friend's parents and I said, &quot;What is your first name?&quot;</td>
<td>In fact, I was in a conversation with one of my friend's parents and I said, &quot;&quot;What is your first name?&quot; And she said what her first name is. And I said,</td>
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And she said what her first name is. And I said, "How would you like me to c--call you--what would you like me to call you? By your first name, by a Christian reference--um--prefix, or your last name? And she said, "Whatever you feel comfortable with." Well, she's my friend's mother, so, you know, I don’t know. I have to decide what I feel comfortable with. But I wanna demonstrate respect and so I think that the difference in the system is that, for some reason, there are some people still who don't believe they should respect clients. And that's a problem. I think.

<p>| Disrespecting Clients | But that is disrespectful, I think, to call someone psychotic when that's not a word I use to refer to myself under any circumstance. So, I mean, more power to the people who do, but I just don't want to call myself any label. Other than my name [laughs]. | But that is disrespectful, I think, to call someone psychotic when that's not a word I use to refer to myself under any circumstance. So, I mean, more power to the people who do, but I just don't want to call myself any label. Other than my name. |
| Treatment that feels Human | [Deep breath] I feel better about our [the psychiatrist and my] relationship. I feel better going to him. Like, I know, he's today's Friday, right? So, like, I missed our appointment--I meant to call him yesterday to say, &quot;I need to come back sooner,&quot; but so--so, I know that he is con-- extremely busy, because the agency doesn't have many psychiatrists. He also works in private practice. So with my, um, psychiatrist in particular, I feel much more comfortable waiting the amount of time that it takes, like sometimes he'll say two months, sometimes he'll say three months. Right now, we're, um, decreasing my medication, so--so I see him more regularly and I think that--um--that I feel much more listened to, much more heard, even though--within the time constraint. So. Yeah. I wish it were true for everyone. I don't--I don't think it's true for everyone. I think--I wish it were true. | I feel better about my relationship with my psychiatrist. I feel better going to him. Today's Friday, right? So, like, I missed our appointment. I meant to call him yesterday to say, &quot;I need to come back sooner.&quot; I know that he is extremely busy, because the agency doesn't have many psychiatrists. He also works in private practice. So, with my psychiatrist, I feel much more comfortable waiting the amount of time between appointments, like sometimes he'll say two months, sometimes he'll say three months. Right now, we're decreasing my medication, so I see him more regularly and I feel much more listened to, much more heard, even within the time constraint. So, yeah. I wish it were true for everyone. I don't think it's true for everyone. I wish it were true. |</p>
<table>
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<tr>
<th>Disrespecting Clients</th>
<th>And I--um--I know that [pause] service providers are human too, right? They have good days, they have bad days. Perhaps I'm giving you an assessment of the second therapist I had on her bad day. You know, I don't know if it was a bad day for her.</th>
<th>And I know that service providers are human too, right. They have good days, they have bad days. Perhaps I'm giving you an assessment of the second therapist I had on her bad day. You know, I don't know if it was a bad day for her.</th>
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<tr>
<td>Lack of Therapeutic Connection</td>
<td>I do know that she was, of the three I had at that agency, she was the least willing to talk about or answer questions that I had about her personally.</td>
<td>Of the three therapists I had at that agency, I do know that she was the least willing to talk about or answer questions that I had about her personally.</td>
</tr>
<tr>
<td>Disrespecting Clients</td>
<td>And while, I mean, I shared some stuff with her, even still, that I know probably was hard to hear, but she still disrespected me I think in that instant, even if it was a bad day. She disrespected me and I carry that, 'cus I've shared that story with other people and they're like, &quot;What, she called you what?&quot; I said, &quot;I know!&quot;</td>
<td>I know I probably shared some stuff with her that was hard to hear, but I think she disrespected me in that instant, even if it was a bad day. She disrespected me and I carry that. I've shared that story with other people and they're like, &quot;What, she called you what?&quot; I said, &quot;I know!&quot;</td>
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<tr>
<td>Feeling Unable to Advocate for Self</td>
<td>I--I couldn't defend myself, 'cus one of the things that I don't do is self-advocate very well. I teach it to other people [laughs], you know, it's one thing to teach it, it's another thing to</td>
<td>I couldn't defend myself, 'cus one of the things that I don't do is self-advocate very well. I teach it to other people. You know, it's one thing to teach it, it's another thing to practice it.</td>
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<td>practice it I think, but I--we--that's the kind of advocacy we teach, self systems and legislative. For years! I--you have to speak up for yourself, I know, but there's--there's something that prevents me from speaking up and it's probably because stuff like that hurt me deeply, like being called a name, hurts me so deep, like to my core, that I don't always have the words to combat it. And also, it's because I know it's either going to hurt me deeply to my core and I'm sensitive or</td>
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<td>But, that's the kind of advocacy we teach: self systems and legislative. For years! You have to speak up for yourself, I know, but there's something that prevents me from speaking up and it's probably because stuff like that hurt me deeply, like being called a name, hurts me so deep, like to my core, that I don't always have the words to combat it. And also, it's because I know it's either going to hurt me deeply to my core and I'm sensitive, or</td>
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| Treatment Based on Appearance |
| I'll get angry about it and I don't want to explode, because the cost of me exploding is much greater [laughs], just because I'm a black woman, it's greater. It's greater for black men; it's greater for black women. And I know that people will say anything--a--i--it happened to me at the Department of Motor Vehicle. The woman was talking to me in a way that I felt you shouldn't talk to human beings like. And instead of saying anything--‘cus I said, |
| I'll get angry about it and I don't want to explode, because the cost of me exploding is much greater. Just because I'm a black woman, it's greater. It's greater for black men; it's greater for black women. And I know that people will say anything. It happened to me at the Department of Motor Vehicle. The woman was talking to me in a way that I felt you shouldn't talk to human beings. And I didn't say anything, 'cus I said, there's a lot of people, a lot of |
there's a lot of people, a lot of witnesses, they won't witness her talking to me in a disrespectful way, they'll witness my response. And so my response was to walk out because I don't want to make a scene, because I will end up one of two places: jail, and I don't want to end up there, I never been there, or a psych ward, and you know--and--and so I--it can't happen. You know. The way I would get treated by law enforcement officers is much greater cost to me.

I learned my lesson and that's the lesson, unfortunately- -is the lesson I learned. That the thing you think won't happen to a human being will most definitely happen to me. And so--so, that's the stuff that makes you cry if you allow yourself. Absolutely. Those are terrible lessons to learn. It is a terrible lesson to learn. But I learned it well.

I can't think--I'm gonna have to apologize to you for--is, uh, talking so
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<tr>
<th>Seeking Treatment</th>
<th>much and, um . . . Not giving you a chance to catch a breath or . . .</th>
<th>chance to catch a breath.</th>
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<tr>
<td>[How old are you now] 51. Mm. [I began receiving treatment at] Oh God, 17. Maybe? But that was--we didn't talk about that. So, um, 17, um, because, um, I had some depression and so--but the mo--the--the part we talked about, I was probably, um, it was probably 1998. So, I was born in '64. So, 35.</td>
<td>I'm 51 now. I started receiving treatment when I was, oh God, 17, maybe? But we didn't talk about that. I had some depression. But, the treatment we talked about probably started around 1998. I was born in 1964, so I was 35.</td>
<td></td>
</tr>
<tr>
<td>Seeking Treatment</td>
<td>I was in--I was in informal trea--I went to--I went to treatment la--I told you I was a birth mother? So, I had my son at 18 in 1982.</td>
<td>Before that, I went to informal treatment. I told you I was a birth mother? So, I had my son at 18 in 1982.</td>
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<tr>
<td>What Propels me Forward</td>
<td>I went and saw a social worker then and that's what prompted me to--my interest in social work, um--um, I think is not having an adoption handled the way mine was handled.</td>
<td>I went and saw a social worker then and that's what prompted my own interest in social work. I think my interest is in not having an adoption handled the way mine was handled.</td>
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<tr>
<td>Seeking Treatment</td>
<td>But--um--so, I wasn't in treatment until 1998 when I was asked to take a leave of absence from--from work.</td>
<td>So, I wasn't in treatment again until 1998 when I was asked to take a leave of absence from work.</td>
</tr>
<tr>
<td>Seeking Treatment</td>
<td>[Deep breath] Y--y--are--d--d--do you consider private care--are you considering private care? Probably it was--probably it was a little bit sooner than 1998, 'cus I went to a-um--uh--psychiatric nurse for a brief stint.</td>
<td>I was in private care a little bit sooner than 1998, because I went to a psychiatric nurse for a brief stint.</td>
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<tr>
<td>Seeking Treatment</td>
<td>Like, I always felt like I needed therapy- -like, I believe in therapy. So that's the first thing. I believe in talking to someone and trying to figure out what's going on with you. Like, other people were saying to me, &quot;You need to talk to someone,&quot; [laughs] &quot;you need to talk to someone, 'cus you're a sick individual.&quot; So, I finally agreed and went to someone and, um, you know I had several diagnoses. She diagnosed me with ADHD and several other diagnoses.</td>
<td>Like, I always felt like I needed therapy. Like, I believe in therapy. So that's the first thing. I believe in talking to someone and trying to figure out what's going on with you. Like, other people were saying to me, &quot;You need to talk to someone. You need to talk to someone, 'cus you're a sick individual.&quot; So, I finally agreed and went to someone.</td>
</tr>
<tr>
<td>The Emotional Impact of the Voices</td>
<td>and then in 1998 I went to a psychiatrist because I couldn't deal with the voices. I would go to my window and look outside and hear things and not see anybody. So, I was surprised when [laughs]--when, you know, it was happening in a classroom. Being in a</td>
<td>And then in 1998, I went to a psychiatrist because I couldn't deal with the voices. I would go to my window and look outside and hear things and not see anybody. So, I was surprised when, you know, it was happening in a classroom. Being in a</td>
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classroom--being in a class and looking outside and--spent a lot of time at work, um, teaching--I was teaching adults then, um. And, you know, finally I just couldn't deny that I was having an experience that probably other people didn't.

class and looking outside and not seeing anybody. I spent a lot of time and work where I was teaching adults. And, you know, finally I just couldn't deny that I was having an experience that probably other people didn't have.

<p>| Hearing Voices | But, for a long time I believed--which is why I didn't do anything about it--I believed that everybody could hear what I was hearing. So--so, I'm still not convinced [laughs] about that [laughs] to be honest with you, hearing voices, which is why I didn't do anything about it. I believed that everybody could hear what I was hearing. So, I'm still not convinced about that, to be honest with you. |
| Hearing Voices | but I do know that they say one in 10--you know, what I've learned from the Hearing Voices Movement is they say one in 10 people hear voices and other people--and--and the problem is not hearing the voices, the problem is how you cope with what--what you experience. So, I think, in part my experience is spiritual and in part it is just, um, my experience. |
| Hearing Voices | And that other people really don't--but, it surprises me, I have to say that, um . . . I know. Yeah, yeah, |
| Hearing Voices | But, it surprises me, I have to say, that other people don't hear the voices. When people said, &quot;No, I don't her |
| <strong>Taking Medication</strong> | when people say, &quot;No, I don't&quot;--you know, I was like, &quot;You gotta be kidding.&quot; But, [laughs] how can you not be surprised? Because they're always with me 24/7. | And so, like I said, the medication only helped calm me. I think it focuses me, that's the impact that I feel. But I take a medication that other people wouldn't be caught dead taking. And so, every time--I used to take the maximum dose of it, I don't take the maximum dose anymore and sometimes I wonder if I should and sometimes I quite frankly wonder if I'm addicted to it and that's the reason I won't stop it completely. 'Cus why take something if you are of the opinion that you don't believe it works at all? I mean, it never worked. |
| <strong>Family Involvement in Treatment</strong> | Yeah. Yeah. Yeah. It is. It is. My family had the biggest influence of--on me other than--and--and they would have conversations with the doctor, so, um, the-- | My family has had the biggest influence on my using medication. They would have conversations with the doctor. |</p>
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<tr>
<th>The Impact of Choosing to take Medication</th>
<th>really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak, but--and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years and, you know, I've done other things I don't like. Like I said, I'm not perfect, but, yeah.</th>
<th>Really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years and, you know, I've done other things I don't like. Like I said, I'm not perfect.</th>
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<td>[I was hospitalized] No, four times. Um, I will say I was hospitalized four times, um, from the period of 1999 to 2004.</td>
<td>I was hospitalized four times between 1999 and 2004.</td>
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<tr>
<td>Treatment that feels Human</td>
<td>One of the hospitals actually had an expressive arts therapy program, so--but I was also isolated from the unit and I probably left there too soon, um, because when I realized I could sign myself out I did and then I tried to go back [laughs] and they wouldn't let me. So--so--so--but that one had art, music, um, it was probably more humane. I was never restrained, but I did get--I couldn't have shoestrings, I couldn't</td>
<td>One of the hospitals actually had an expressive arts therapy program. But, I was also isolated from the unit. I probably left there too soon, because when I realized I could sign myself out, I did and then I tried to go back and they wouldn't let me. But that hospital had art and music; it was probably more humane. I was never restrained,</td>
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Dehumanizing Experiences

And so, in some respects, um, that kind of treatment for someone who, um, I'll just be honest about it: that kind of treatment for someone who has a higher level of testosterone, 'cus I do, um, and grow a beard, um, because I started shaving, um, the hair on my face instead of waxing it, to not be able to use anything to shave--so, I really had a full grown beard and the impact that that had on my self esteem in the hospital can't be underestimated. Because other people--I usually don't allow the public to see me like that and so other patients, nurses, doctors, everybody saw me with a full grown beard. And because I wasn't allowed to take care of it without, um, people seeing me. So, but I couldn't have shoestrings, I couldn't shave, I couldn't do anything like that. So, I'll just be honest about it: I have a higher level of testosterone and grow a beard, because I started shaving the hair on my face instead of waxing it. So, I really had a full grown beard and the impact that that had on my self esteem in the hospital can't be underestimated. I usually don't allow the public to see me like that and so other patients, nurses, doctors, everybody saw me with a grown beard. And I wasn't allowed to take care of it without people seeing me.
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<th>Themes</th>
<th>Meaning Units</th>
<th>Transformation 1</th>
<th>Transformation 2</th>
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<tr>
<td>Care I Receive Now</td>
<td>Well I have a therapist and--who's a psychologist or a social worker--and then I have a psychiatrist who I only see every couple of months or so for medication basically. And I was in a group therapy also, um, but right now, um--I lost my mother in July, so . . . Yeah, thank you. So, I'm in a grief support, um, group so I--I'm not going to the, uh, other group because it meets about the same time.</td>
<td>Well, I have a therapist. I also have a psychiatrist who I only see every couple of months for medication. I was in group therapy also, but after I lost my mother in July I started a grief support group instead.</td>
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<tr>
<td>Care I Receive Now</td>
<td>Hm. Well, since it's a clinic, um, I've had changes of therapists and things like that . . . But, um, I'd say, at least maybe two, three years. Yeah. [I've been at that clinic] Um, let's see, since about 2006, so almost 10 years I guess, yeah. Yeah.</td>
<td>I've been going to the same clinic for therapy for almost 10 years, I guess. I've had to change therapists a few times, but I've been with my current therapist for at least two or three years.</td>
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<tr>
<td>Where I Receive Care</td>
<td>No, the [grief counseling] is through a community center. Well that's what I'm talking about. Oh, sorry. Yeah, the group therapy was in a hospital.</td>
<td>The grief support group is through a community center. The group therapy was in a hospital.</td>
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<tr>
<td>Trauma and Stress in My Life</td>
<td>Well, um, I have a history of sexual abuse by my grandfather, um, so somewhat that, posttraumatic stress, and then, um, I suffer from major depression and anxiety, um, but for the past I'd say 10 years, maybe less than that, I've been the primary caregiver for my mother, who had, um, dementia and they also said maybe some Alzheimer's, but I think it was more the vascular dementia. And, um, then a lot of physical problems that were going on, but I also, in the course of that, became estranged from my sister and brother. So, that was like an ongoing problem for me and a great stress.</td>
<td>I was sexually abused by my grandfather, so I suffer from posttraumatic stress in addition to major depression and anxiety. For the past 10 years, maybe less than that, I've been the primary caregiver for my mother, who had dementia and a lot of physical problems. I also, in the course of that, became estranged from my sister and brother. So, that was like an ongoing problem for me and a great stress.</td>
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<tr>
<td>How My Family Felt</td>
<td>Well, um, in the past, um--well, when I first started out, um, it was kind of hit or miss, because my parents were not behind me, really, getting involved in therapy. They're from a different generation altogether. And they didn't want people knowing that I was going to be in care.</td>
<td>My first attempts to find care were kind of hit or miss, because my parents were not behind me getting involved in therapy. They're from a different generation altogether and they didn't want people knowing that I was going to be in care.</td>
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<tr>
<td>How I Got Connected to Care</td>
<td>So, I actually spoke to, um, a woman who I was told by a professor of mine that sometimes people when they're not living up to their intellectual potential have psychological problems going on, so he wanted me to see her. And so I contacted her and at that point I was working, um, in advertising so, um, I contacted her and she gave me the name of this person, but it was kind of weird because it seemed like it was more he was interested in giving me meds and he couldn't see me regularly, so, um, you know, so it was mostly give me pills.</td>
<td>A professor of mine told me about a woman who people sometimes spoke to when they're not living up to their intellectual potential or have psychological problems going on. He wanted me to see her and so I contacted her. At that point, I was working in advertising. She gave me the name of this person to go see, but it was weird and he couldn't see me regularly and was more interested in giving me meds.</td>
<td>A professor of mine told me about a woman who people sometimes spoke too when they weren't living up to their intellectual potential or when they were having psychological problems. He wanted me to see her and so I contacted her. At that point, I was working in advertising. She gave me the name of this person to go see, but it was weird and he couldn't see me regularly and was more interested in giving me meds.</td>
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| My Experiences with Care | and then he wanted to do this hypnosis thing and so I said, "Well, alright, I'll try it." But, um--and it went-really, it was just more--more of a deeper, um, feeling and emotional, you know--touching your emotions more deeply. I was pretty much aware of what was going on, so I mean there was no way that he could have taken advantage or anything like that. Then he wanted to do this hypnosis thing and so I said, "Well, alright, I'll try it." Really, it was just about touching your emotions more deeply. I was pretty much aware of what was going on, so, I mean, there was no way that he could have taken advantage or anything like that. | Then he wanted to do this hypnosis thing and so I said, "Well, alright, I'll try it." Really, it was just about touching your emotions more deeply. I was pretty much aware of what was going on, so, I mean, there was no way that he could have taken advantage or anything like that.
### Deciding When to Enter a Hospital

| But, um, so, then at one point, um, you know, we had talked about me going to this, um, live-in place, but when I spoke to the people there they said, "But you're working and really you should continue with that if you possibly can and just do outside therapy." |

### Care that Made it Worse

| So. So, that's when I got involved with my--he was actually a psychiatrist and--slash psychoanalyst and I think [sigh], looking back on it, it triggered, I think, my post traumatic stress, because he was an older man and, of course, my grandfather was an older man. He also had this, like, walk down type of office and he had like this couch-type thing, but he didn't have me on the couch, he had me sitting up. But I just started getting worse and hearing voices and I started hallucinating things and I was in and out of hospitals. So, I wasn't doing well at all. His type of therapy, where you don't even say hello to the person, that was not for me at all. | So, that's when I got involved with my psychiatrist slash psychoanalyst. I think, looking back on it, it triggered my posttraumatic stress, because he was an older man and, of course, my grandfather was an older man. He also had this, like, walk down type of office and he had like this couch-type thing, but he didn't have me on the couch, he had me sitting up. But I just started getting worse and hearing voices and I started hallucinating things and I was in and out of hospitals. So, I wasn't doing well at all. His type of therapy, where you don't even say hello to the person, that was not for me at all. | So, that's when I got involved with my psychiatrist slash psychoanalyst. I think, looking back on it, that working with him triggered my posttraumatic stress, because the psychiatrist was an older man and my grandfather had been an older man. He also had a walk down type of office and he had couch-type thing. He didn't have me on the couch, he had me sitting up. But I just started getting worse and hearing voices and I started hallucinating things and I was in and out of hospitals. So, I wasn't doing well at all. His type of therapy, where you don't even say hello to the person, that was not for me at all. |
hallucinating and things like that and I was in and out of hospitals--into the hospital. So, I wasn't doing well at all, um, [pause] and, um, [pause] his type of therapy, which was that you don't even say hello to the person, that was not for me at all. It was just so impersonal. And then, um, he had other, you know, things that he--really wouldn't talk that much at all, he d--and he could sit there and sometimes I would just be--couldn't talk and I would just be looking at the floor and there would be silence for almost 50 minutes and so that was not really conducive to me speaking or feeling comfortable or anything like that.

It was just so impersonal. And then he really wouldn't talk that much at all and sometimes I couldn't talk and I would just be looking at the floor and there would be silence for almost 50 minutes and so that was not really conducive to me speaking or feeling comfortable or anything like that.

I think so, because, um, at one point I--I said to him, "Well, um, I think I really need to deal with"--I had been with this artist for a year and, um, I was in love with him. He was an older man though and he had gotten into debts and decided he needed to go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided that's where he was gonna go, but I had been with this artist for a year and I was in love with him. He was an older man though and he had gotten into debts and decided he needed to go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided that's where he was gonna go, but
go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided well that's where he was gonna go, but that just really hit me badly and, um, [pause] I just--that's when I kind of ended up, uh, in the hospital and--and--um, you know, when I tried to say, "Well, I think there's something here and I don't know--I'm not dealing well with his leaving" and all that and--but he just thought, "Well, there's nothing to do with that."

Not Being Listened to About Medication

And at that point he had, you know, said I was paranoid schizophrenic and, um, so then he was pushing all these heavy-duty tranquilizers--so called tranquilizers and I kept telling him, "They're having a paradoxical effect on me." Which I didn't know at that point about paradoxical effects but I do at this point. So I'd say to him, uh, "I'm feeling worse and I'm feeling more anxious and more paranoid" and all this and he'd say, "No, no,

And at that point he had said I was paranoid schizophrenic and so then he was pushing all these heavy-duty so called tranquilizers and I kept telling him, "They're having a paradoxical effect on me." I didn't know about paradoxical effects at that point, but I do at this point. So, I'd say to him, "I'm feeling worse and I'm feeling more anxious and more paranoid" and all this and he'd say, "No, no, no. You can't possibly, because
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<tr>
<th>How My Family Felt</th>
<th>And so, um, eventually--um--well, my parents and my father especially was very mad, um, about me continuing to see him.</th>
<th>My parents and my father especially was very mad about me continuing to see the doctor.</th>
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<tr>
<td>Not Trusting Self</td>
<td>and I don't know, I just was so sick and then I felt like, well if I give up on this then am I just being--you know, kinda wimping out and I'm not, you know--maybe I need to hear what he's saying or need to do this or--</td>
<td>I was just so sick and then I felt like, well, if I give up on this then I am just kinda wimping out and maybe I need to hear what he's saying or need to do this,</td>
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<tr>
<td>Finding New Care</td>
<td>but, um, that finally--we ended, because we kinda got into this tiff with each other and, um, I had already started to--to ask about another therapist and that type of thing, so, um--and so that's--that--we did end and so that was probably the best thing anyways, [chuckles] so.</td>
<td>but finally we ended, because we kinda got into this tiff with each other and I had already started to ask about another therapist. So, we did end and that was probably the best thing anyways.</td>
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<tr>
<td>Lack of Continuity with Care</td>
<td>But--but, I'm not--my present therapist, now--unfortunately, it's a clinic, so I've had to go through different changes.</td>
<td>Unfortunately, I receive care through a clinic now, so I've had to go through different changes with my therapists, because they leave to do</td>
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<tr>
<td>Lack of Connection with Therapist</td>
<td>but this person right now, I don't know, we're kinda going through a--a weird situation where he's saying things or doing things that are just making me more anxious and . . .</td>
<td>I'm going through a weird situation with the therapist I see now, where he's saying or doing things that are just making me more anxious.</td>
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<tr>
<td>Feeling Anxious about Capabilities</td>
<td>Well, for instance, um, I've been having this problem with Department of Motor Vehicles, 'cus unfortunately my insurance company, um, made a mistake and, why they did this I don't know, but the guy transferred funds I had already paid them to this new, lower fee insurance that we're going to start in October. But you don't take the insurance away from a person and make it look like I didn't have any insurance. So, DMV sends me this letter that I'm not gonna be able to register my car because, um, I didn't have insurance from . . .</td>
<td>For instance, I've been having this problem with Department of Motor Vehicles, 'cus unfortunately my insurance company made a mistake and transferred funds I had already paid to this new, lower fee insurance that we're going to start in October. But you don't take the insurance away from a person or make it look like I didn't have any insurance. So, DMV sends me this letter that I'm not gonna be able to register my car because I didn't have insurance from June until October. Things like that just get me very anxious and I'm</td>
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June until October. So, things like that just get me very anxious and I'm never sure that I'm gonna be capable to, you know, take care of them and handle them.

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<th>Getting Support</th>
<th>and--well, so he--I wasn't able to get on to the website with this, um--we have a resident advisor whose really very nice and everything--for some reason we couldn't get on, but she decided to call the insurance company and see if she could get somewhere better with them, 'cus I thought I had solved the problem and everything talking to someone at the insurance company and apparently that may not have been the case, 'cus then she talked to someone and they did actually send us in an email exactly what they were gonna send to DMV and that other person hadn't done that. And I said to her, &quot;Well, how come you could get somewhere when I</th>
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<td>I wasn't able to get on the website myself and we have a resident advisor who's really very nice and everything and for some reason we couldn't get on together either. But she decided to call the insurance company and see if she could get somewhere better with them, 'cus I thought I had solved the problem and everything talking to someone at the insurance company and apparently that may not have been the case, 'cus then she talked to someone and they did actually send us in an email exactly what they were gonna send to DMV and the person I talked to hadn't done that. And I said to her, &quot;Well, how come you could get somewhere when I</td>
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<tr>
<td>Not Trusting that I'll Be Treated Well</td>
<td>And I'm just thinking that maybe they see that another person knows what's going on and so they better make sure that they correct the person. It's kinda like having a witness to what's going on and so they better make sure that they correct the person. Of course I have trust issues and so that's why I kind of get all upset about, well is this gonna be taken care of or not and all that, so, but.</td>
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| Lack of Connection with Therapist | Well, what he did, oh yeah, I didn't finish the [laughs]--okay, so what he did was, he gets on the website by some--whatever and, um, he goes, "Alright, give me your, uh, license and I'll pu--put in all your date of birth and your everything and." So he gets onto the website, but what it says is that I owe this penalty of 200 dollars. And I said, "What!" But I said, "Well, we just sent the proper things, so maybe the other person didn't send it or DMV is so behind", 'cus they changed over their computers and--but then he's saying to me, "Well, I think you should go down their in person." And I said, "How do you think I'm going to stand there for two hours? I can hardly stand." I have a lot of arthritis pain. So, I said, "I can't stand for 15 minutes, so I'm not gonna be able to stand for two hours or more." Well, see now you've gotten me all upset about something that I felt okay about." So, he laughs and he thinks it's funny. And, lately, he's done that. He thinks things are funny when I don't think they're funny. But anyway, the resident adviser said, "No, just wait and...
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<th>Topic</th>
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<tr>
<td>Not Understanding Therapist</td>
<td>Um, well [sigh], I guess yeah, somewhat, now. I dunno what's going on with him or maybe he's just really in a Christmas mood and I'm just this year, I'm not in a Christmas mood and I dunno.</td>
<td>I dunno what's going on with him. Maybe he's just really in a Christmas mood this year and I'm not.</td>
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<tr>
<td>Making Decisions About Care</td>
<td>But, I kind of ended up with him, 'cus I was in the intensive outpatient there and I had been seeing this woman who I liked, but she had told me that she was taking on a different job there, so she wouldn't be able to see me every week. And I felt, um, because of my whole situation, my mother and</td>
<td>I ended up seeing him 'cus I was in the intensive outpatient there and I had been seeing this woman who I liked, but she told me that she was taking on a different job there, so she wouldn't be able to see me every week. And I felt that because of my whole situation, my mother and everything, that I</td>
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everything still, um, that I needed to see someone every week. So, that's why I ended up switching to this other therapist. And, um, [pause] for a while it seemed to work, but I dunno, it's just.

needed to see someone every week. So that's why I ended up switching to this other therapist. And for a while it seemed to work.

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<th>Care that Feels Better</th>
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<td>Well, yes. When I, um, finally ended up, um, going into--well, I ended up, um--after seeing him, I was with, like, a psychologist and then, um, he worked with a psychiatrist. So, I found I liked that interaction better and--you know, and he was a friendly person and he would say--actually say &quot;Hello&quot; and you know and all that and &quot;How're you doing?&quot; and so there was interaction and he would talk to me and not just me spouting off for 50 minutes and maybe an &quot;mm&quot; or an &quot;ern&quot; or something like that. And so I like to have dialogue and have someone give me feedback about what I'm saying. Yes. Yeah. Hm.</td>
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<td>After I saw the psychiatrist who did psychoanalysis, I worked with a psychologist who worked with a different psychiatrist. I found I liked that interaction better. He was a friendly person and he would actually say &quot;hello&quot; and so there was interaction and he would talk to me and it wasn't just me spouting off for 50 minutes and maybe getting an &quot;mm&quot; or an &quot;ern&quot; or something like that. I like to have dialogue and have someone give me feedback about what I'm saying.</td>
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<tr>
<td>Care that Didn't Feel Helpful</td>
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<td>Care that Feels Better</td>
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<td>Speaking Up for Needs</td>
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um--I guess the director. And he said, "Well, I'm not going to keep anybody out of a program just because their insurance won't pay, so"

<p>| Not Having Needs Met | but, she made it so I could only stay for--I don't know if it was eight weeks or something like that. And at the end of that, even the staff said to me, &quot;Well, we were surprised at your having to leave or your going to leave.&quot; And I said, &quot;Well, it isn't my choice. She's saying I have to leave.&quot; And so it's too bad they didn't kind of try to say, &quot;Well, look, she really needs to stay in this.&quot; 'Cus there seemed to be some kind of, unfortunately, battle there of who was gonna be in charge of the care or whatever. And, um, so that wasn't my intention but it ended up that way. So that was an unfortunate thing, 'cus I didn't feel like I could stand up and say, &quot;Look, I really need to continue on with this. And so we need to figure a way out.&quot; | But, she made it so I could only stay for eight weeks or something like that. And at the end of that, even the staff said to me, &quot;Well, we were surprised at your having to leave or your going to leave.&quot; And I said, &quot;Well, it isn't my choice. She's saying I have to leave.&quot; And so it's too bad they didn't kind of try to say, &quot;Well, look, she really needs to stay in this.&quot; 'Cus there seemed to be some kind of, unfortunately, battle there of who was gonna be in charge of the care or whatever. So that was an unfortunate thing, 'cus I didn't feel like I could stand up and say, &quot;Look, I really need to continue on with this. And so we need to figure a way out.&quot; |</p>
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<tr>
<th>Speaking Up for Needs</th>
<th>But, I guess--because I knew that this was really triggering me and so I knew, therefore, that this was a needed, um, treatment and program, but . . . Right.</th>
<th>Because I knew that this was really triggering me and so I knew, therefore, that this was a needed treatment program.</th>
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<tr>
<td>Being a Leader</td>
<td>Well, there was one time when I was doing--I ended up being the leader, which I didn't intend, but people kind of had me as the leader of the trauma research group.</td>
<td>I ended up being the leader of the trauma research group, which I didn't intend initially.</td>
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<td>Traumatic Experience</td>
<td>And at one point, I was taking one of the members home--giving him a ride, and he disclosed to me that he not only was a trauma victim, he also molested young kids. And that just really freaked me and got me triggered, because my own thing was of being a young child and being molested.</td>
<td>And at one point, I was giving one of the members a ride home, and he disclosed to me that he not only was a trauma victim, but he also molested young kids. And that just really freaked me out and got me triggered, because my own thing was of being a young child and being molested.</td>
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<tr>
<td>Not Having Needs Met</td>
<td>So, I went to my, um--I guess I, uh--the head of the, um, rehab area there, that I was in, and they were trying to convince me that no, I shouldn't say anything to anybody, because that might, um, upset this guy and, um, I should keep this under wraps. And I said, &quot;But that isn't fair to me.&quot;</td>
<td>So, I went to the head of the rehab area that I was in there and they were trying to convince me that I shouldn't say anything to anybody, because that might upset this guy and that I should keep this under wraps. And I said, &quot;But that isn't fair to me.&quot;</td>
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wraps. And I said, "But, that isn't fair to me, I mean."

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<tr>
<th>Speaking Out</th>
<th>So finally, in one of our group meetings, um, I just--I said, &quot;I'm sorry, but I'm not going to be able to not say this to everyone in this group and, um, you know, I'm sorry if this upsets this particular person, but I'm upset and I'm triggered and I need someone to help me with this and maybe some of the other people do also.&quot; So, we then had, um, a woman that worked in their emergency services and she actually was a trauma specialist, so she came into some of our groups, then.</th>
<th>So finally, in one of our group meetings, I just said &quot;I'm sorry, but I'm not going to be able to not say this to everyone in this group and, you know, I'm sorry if this upsets this particular person, but I'm upset and I'm triggered and I need someone to help me with this and maybe some of the other people do also.&quot; So, we then had a woman that worked in their emergency services and she actually was a trauma specialist, so she came into some of our groups.</th>
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<td>And then I--actually, after that I became her, um, one of her patients or clients, um, after that, so.</td>
<td>And then I actually became one of her patients or clients after that.</td>
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<td>Not Being Dealt a Fair Option</td>
<td>Well, unfortunately, I haven't had such a good experience as far as I was trying to go back to work, um, and I feel there I was not dealt a fair, um, option.</td>
<td>Unfortunately, I haven't had such a good experience as far as trying to go back to work and I feel that I wasn't dealt a fair option in that area.</td>
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Not Being Treated with Respect

Because, first of all, I had someone who kinda treated me like-well--an--well she would go into the interviews and I guess people didn't realize that I had the mental health background and she would just put that out first before they even met me . . . No, this was actually a staff person who was supposed to be in vocational, um, services for people. The vocational services staff person I worked with would go into the interviews she set up for me and would tell them that I had a mental health background before they even met me.

Not Being Treated with Respect

And, um, you know, so at one point I said to her, um--'cus I had gotten to the place where we were going to interview and she wasn't there and I kind of panicked and "What do I do now?" And then it got to be late and it was almost time for the interview, so I figured I better just go in and then she all of the sudden flips into--what's--with her car and makes a turnaround and goes back out and I'm thinking, "What's going on?" And then she gets there and I said, "Well, what happened to you? I don't understand." And she goes, "Well, if you
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<th>Feeling Uncertain of Whether Needs Will Be Met</th>
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<td>were so concerned, why didn't you make the call yourself? You--you--you could make the call yourself.&quot; And I said, &quot;Well then what do I need you for then?&quot;</td>
<td>And then we go in and, um, I guess this particular woman didn't know that I was coming with her. And so she kind of, like, looked at me like--you know--this look like, &quot;What're you doing here?&quot; And so that got me even more, you know, within myself and I thought, &quot;Oh gosh.&quot; And then, um, so she took, you know, the vocational person in and talked with her and then, you know, she came out and then she was warmer and she offered her hand to me and said, &quot;Well, come on in.&quot;</td>
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<td>yourself? You could make the call to the company yourself.&quot; And I said, &quot;Well then what do I need you for then?&quot;</td>
<td>And then we go into the interview and I guess the interviewer didn't know that I was going to be there with the staff member. So she kind of looked at me like, &quot;What're you doing here?&quot; And so that got me even more within myself and I thought, &quot;Oh, gosh.&quot; So she took the vocational person in and talked with her and then she came out and she was warmer and offered her hand to me and said, &quot;Well, come on in.&quot;</td>
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<td>Not Having Needs Met</td>
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<td>I shoulda made the call to this particular printer, 'cus I was in graphic arts and so we were looking into printers and different places like that for me to work. So--so, that got me upset, 'cus we're getting into a little tiff before we even get into the interview place.</td>
<td>So, that got me upset, 'cus we're getting into a little tiff before we even get into the interview place.</td>
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<td>Issue</td>
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<td>Not Being Offered a Chance</td>
<td>And most times, when the people did meet me, um, you know, they seemed to find something that they would, you know, um, say that was good about my artwork or this or that. Um, but at that point they all wanted me to know the computer, which I had never gotten into, so. The thing was that they had had--you know, I said, &quot;Well, could I do an internship?&quot; And they said, &quot;Well, no, because we've had people in the past and it hasn't worked out.&quot;</td>
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<td>Being Looked Down On</td>
<td>So, um--and also with vocational services, I found the same type of thing where they kind of were looking down at a person with a mental illness and not giving me a fair try at things and--and that type of thing.</td>
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<td>Not Being Listened to About Medication</td>
<td>Um, well, yeah. I had--when I was in the intensive outpatient, um, they had brought in a new psychiatrist who, um, was supposed to be for the particular group I was in, so he was not my regular psychiatrist. And there was a certain medication that I was using and he was against me having it and using it. He said,</td>
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using and he just was against me having it and using it. And he said, "Well, no, no, no. You're going to be going off of this." And I said, "You will give me no quality of life, then," I said, "and I don't think that that is fair." But he was sticking to his guns and he wasn't going to give me the refill and then I guess the pharmacy said, "Well, this is not a medication you should take her off of, you know, just like that." And, um, you know, so he said to me, "But I thought we agreed." And I said, "But I didn't agree to go off of it like that, completely. And you said we could try going down on it and I agreed to that but I didn't agree to not at all."

| Making Decisions About Care | So, I got pretty upset, crying and stuff, to my, um, regular psychiatrist and he said, "Well, do you want me to speak to him?" And I said, "Well, I don't know that that's a good idea." And I said, "I don't know." So, finally, this new psychiatrist said, "Okay, I'm gonna allow you to stay on | So, I got pretty upset, crying and stuff, to my regular psychiatrist and he said, "Well, do you want me to speak to him?" And I said, "Well, I don't know that that's a good idea." So, finally, this new psychiatrist said, "Okay, I'm gonna allow you to stay on |
"Okay, you know, um, I'm gonna allow you to stay on that medication." And--um--and he said, "Because you said to me, well, it would affect your quality of life and so, um, you know, you can stay on that, so." But, that put me through some trauma for a while, um,

Making Decisions About Care

and now, again, this psychiatrist is telling me that I really should get off of that medication, that it's been linked with, um, Alzheimer's and that type of thing. And--um--but in--in doing this--um, it was after my mother died and I'm really not in a good place at this point and so I finally, when I saw him again, I had, you know, tried not using it and just using it sparingly and all that and then I said to him, this past time I saw him, um, I said I would sign something, you know, releasing him from any, um, responsibility of anything, I said, but I don't think I can completely do without this or having it available if I did need it or whatever. And so he said, "Well, you don't have to sign anything, I'll just put it in your chart."

Now my regular psychiatrist is telling me that I really should get off of that medication, that it's been linked with Alzheimer's and that type of thing. But since my mother died I'm really not in a good place at this point. So, I had tried not using it and just using it sparingly and all that. But this past time I saw him I said I would sign something releasing him from any responsibility of anything, I said, but I don't think I can completely do without this or having it available if I did need it or whatever.
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<tr>
<td>Medication Not Working</td>
<td>Yeah. Medication has not worked well for me, um, even now, um, Medication has not worked well for me, even now.</td>
<td>Medication has not worked well for me, even now.</td>
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<tr>
<td>The Effects of Medication</td>
<td>it seems that, well the medication I'm talking about, which, um, is Lorazepam or Ativan, and I've tried to explain that that seems to put me in a more--I don't know, maybe less depressed mood and more, um, wanting to live and wanting to--and be able to, um--I dunno,</td>
<td>The medication I'm talking about, Lorazepam or Ativan, seems to put me in a less depressed mood and to make me want to live.</td>
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<tr>
<td>Feeling Unable to Seek People Out</td>
<td>I have a great fear of people and I--I feel that goes back to my trauma and it wasn't only that trauma, with my grandfather, but I think that was the biggest one. And so I have a fear of people and so where other people would--would gravitate to people and, you know, want to seek them out and talk to them. [tearful] I'm not--I can't always do that, especially if I feel in a really depressed, um, way and I just can isolate myself I have a great fear of people that I feel goes back to my trauma and it wasn't only that trauma, with my grandfather, but I think that was the biggest one. So, I have a fear of people and where others would gravitate to people and want to seek them out and talk to them, I can't always do that, especially if I feel in a really depressed way. I can just isolate myself and not reach out to people.</td>
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<tr>
<td>How Family Impacts Coping</td>
<td>Of course that's my upbringing too. My father was a big one for not telling people your bad things and just being upbeat and good. And, I mean, to an extent I have incorporated his--um--his need for humor, because I do use humor a lot of times to--um--kind of the opposite of what I'm feeling and so I'll seek out maybe a TV program that's funny and, you know, use, um, humor to kind of help me out. [Tearful]</td>
<td>Of course that's my upbringing too. My father was a big one for not telling people your bad things and just being upbeat and good. And to an extent I have incorporated his need for humor, because I do use humor a lot of times in ways that are kind of the opposite of what I'm feeling. So, I'll seek out a TV program that's funny and use humor to kind of help me out.</td>
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<td>Sorry. We have no Kleenex. [Laughs] Alrighty, thank you. [Interviewer leaves the room and returns] Oh, thanks. Oh, thank you.</td>
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<tr>
<td>Trauma and Cutting</td>
<td>Yeah. [Pause] And in fact at one point in my life--um--and I didn't realize it was related to the trauma until I went into the hospital's trauma group. Um, I started cutting and I just couldn't seem to stop myself. I was using razor blades and then</td>
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<td>Razor blades and then, at one point--</td>
<td>'cus I was a biology major in college and graduated with a biology, you know, bachelor of science degree</td>
<td>I was a biology major in college and graduated with a bachelor of science degree in biology.</td>
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<tr>
<td>Trauma and Cutting</td>
<td>and so then I was using a--the, um, scalpel and all that. And then my father found that out and he took that away. But, um, it seemed I couldn't, uh, stop doing it and I just hated myself and I would burn myself and--well at one point I used our electric carving knife on myself. And I just really hated myself and at that point in my life I was blaming myself for the whole sexual thing and I thought I must have done something to get my grandfather to do that. And so of course in the trauma group I learned that wasn't the case.</td>
<td>I was using a scalpel, but my father found that out and he took that away. But it seemed I couldn't stop doing it and I just hated myself and I would burn myself. Well, at one point I used our electric carving knife on myself. I just really hated myself and at that point in my life I was blaming myself for the whole sexual thing and I thought I must have done something to get my grandfather to do that. Of course, in the trauma group, I learned that wasn't the case.</td>
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<td>Love Ended Cutting</td>
<td>but--um--but it wasn't until I started taking care of my nephew, [tearful] until he went to, um, kindergarten--um, he was a baby, my sister had him and her first husband,</td>
<td>But it wasn't until I started taking care of my nephew before he went to kindergarten that I stopped cutting. My sister had him with her first husband, who she's</td>
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who she's divorced from, and, um--but she was going back to work and at that point I wasn't workings, so, you know, she asked me if I'd want to take care of him and I said, "Alright." And, um, so I just really felt close to him and he felt close to me and it was love I needed and, um, [tearful] I stopped cutting at that point, um.

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<th>Trauma and Cutting</th>
<th>And it wasn't until I--I, at one point, I guess, was in--I dunno if I was at the hospital,</th>
<th>At one point, I was at the hospital,</th>
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<td>Speaking Up for Needs</td>
<td>they had finally put together a trauma group there and--even though they kept fighting us about that and, uh, I said you've got recidivism even though you don't do, um, trauma work and I think you need to address the trauma part of it or you're still gonna keep having people with recidivism and all that.</td>
<td>they had finally put together a trauma group there, even though they kept fighting us about that. I said, &quot;I think you need to address the trauma part of it or you're still gonna keep having people with recidivism and all that.&quot;</td>
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| Trauma and Cutting | So, um, I finally went to their trauma program, but then at one point, I needed to call my therapist who was the trauma--she was, um, very knowledgeable in | So, I finally went to their trauma program, but at one point I needed to call my therapist who was very knowledgeable about trauma and I said to her, "It's been
My Experiences with Care

| trauma and I said to her, "It's been years and I haven't felt like cutting, but I feel like it now." And so she said, "Well, I think it's the trauma work," and she said, "if you really think you can't stop yourself, then you need to go to the hospital, but if you think maybe you can, um, do some journaling or something like that to get yourself away from feeling like that." So, luckily, I was able to not do any cutting and so that, hopefully, is the end of that. But, I guess you always have that fear of not knowing what will happen. |
|---------------------------------|---------------------------------|
| years and I haven't felt like cutting, but I feel like it now." And so she said, "Well, I think it's the trauma work," and she said, "if you really think you can't stop yourself, then you need to go to the hospital, but if you think maybe you can, do some journaling or something like that to get yourself away from feeling like that." So, luckily, I was able to not do any cutting and so that, hopefully, is the end of that. But, I guess you always have that fear of not knowing what will happen. |
| Some therapists keep a dialogue and will kind of talk to you, "Well, okay, you said that, so I see how that related to that," but I haven't had all that many who have been that astute or whatever you want to call it to, you know, do--do that type of thing. |
| Some therapists keep a dialogue and will kind of talk to you, "Well, okay, you said that, so I see how that related to that," but I haven't had all that many who have been that astute or whatever you want to call it. |

Um, yeah, I think so. Um--um [pause], like some of them, you know, keep a dialogue and will kind of talk to you about, "Well, okay, you said that, so I see how that relates to that," but, I haven't had all that many who have been that astute or whatever you want to call it to, you know, do--do that type of thing. |
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<td>Not Having Needs Met</td>
<td>And, uh, as far as like doing the trauma part of it, I feel like that's still something that needs to be addressed and I don't feel like I'm with a person that I would do it with. So, um. Right. Yeah.</td>
<td>And as far as doing the trauma part of it, I feel like that's still something that needs to be addressed and I don't feel like I'm with a therapist that I would do it worth.</td>
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<td>Feeling Anxious about Capabilities</td>
<td>Well, I don't have, um, addiction as far as drugs or alcohol, that type of thing, um, I do over eat though, but--um--and that's not good, I'm not saying it's good, but, um, [pause] you know, a— I don't have addiction as far as drugs or alcohol, but I do over eat.</td>
<td>Some people have encouraged me about trying to pursue my art and all that, but, I dunno. I've always found it hard, even when people have been artists themselves and they've looked at my work, I've still felt like they can't be telling me the truth. They're saying it's good, but how do I really know. I just kinda doubt myself and all that. But, they've tried to build me up and tell me positive things.</td>
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<td>How Family Impacts Coping</td>
<td>I think some have, um, encouraged me about, like, trying to pursue my art and all that, but, I dunno. I've always found it hard to, um--even when people have been artists themselves and they've looked at my work, I've still felt like, well, they can't be telling me the truth, you know, they're saying it's good but how do I really know and I just kinda doubt myself and all that. But, I mean, you know, they've tried to build me up and, um, tell me positive things.</td>
<td>One of the first psychiatrists that I was with for about</td>
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um--the psychiatrist that I was with for about ten years, um, at one point he said to me--and he said it to my parents to, he said, "I, you know, get her feeling better about herself and then she comes home to the family life and she's down again and being taken down," and he said, "that's not working to help her." So.

| Not Being Treated with Respect | Um, well, some--some are--um--well, not with the, uh, vocational part, I don't feel. Yeah. Well, I was with, um, one employment support person--and, um, it wasn't just my opinion of what was going on, but it was other people that then saw what was going on and she was like putting all these stumbling blocks in front of me. | One of the vocational support people was putting up all these stumbling blocks in front of me. And it wasn't just my opinion of what was going on, but it was other people that then saw what was going on. |
| Care that Feels Better | and, um, they were, like, helping me to go to school--go back to school for the computer and for, um, graphic arts and also for, um, multi-media. So I have like an Associate of Science from a community college and that. | They were helping me to go back to school for the computer and far graphic arts and multi-media. So I have an Associates of Science from community college. |
| Not Being Treated with Respect | But she just--for some reason, um, she would send me to the financial aid people with the wrong information and the wrong dates and all sorts of things like this. And they'd say to me, "Now she knows what to do, I don't understand what she's pulling here." | But, for some reason, she would send me to the financial aid people with the wrong information and the wrong dates and all sorts of things like that. And they'd say to me, "Now she knows what to do, I don't understand what she's pulling here." |
| Care that Feels Better | And one time--and at this point I would have the person who was supporting me through my, um, education part--I would have her sit in on my meeting with my employment support person. And at one point, she said to me-- | I would have the person who was supporting me through my education sit in on my meetings with my vocational support person. |
| Speaking Up for Needs | and now, she's the one that gave me the wrong dates and everything and the guy at financial aid said, "Well, I have to wipe this out and I have to put this down as the date, otherwise you're gonna be going back and forth here with this paper for no reason." And I said, "Well, you better initial it or something." | The guy at financial aid said, "Well, I have to wipe this out and I have to put this down as the date, otherwise you're gonna be going back and forth here with this paper for no reason." And I said, "Well, you better initial it or something." |
| Not Being Treated with Respect | And so, when we got into the meeting with her, she goes to me--she's like looking all the sudden at me and | And so when we get into the meeting with the vocational support staff, she's like looking all the |
with this smile and she goes, "Well, now you're an artist," she goes, "so what's to stop you from whiting this out and putting in a different writting something different in there?"
And the woman, um, from employment support said to her, "Why on earth would you say that to her? That doesn't apply at all." And she goes, "She's never done anything that's been underhanded or, you know, not decent or honest."

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<tr>
<th>Speaking Up for Needs</th>
<th>So, finally, after having humiliated--humiliating things with her, I finally did switch with the help of, um--an advocate came in and we talked with her boss and I just switched to somebody else.</th>
<th>So, after having humiliating experiences with her, I finally did switch with the help of an advocate who came in and we talked with her boss and I just switched to somebody else.</th>
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<td>Not Being Treated with Respect</td>
<td>But then, I came across this woman that was supposed to help me with updating my, um, resume. And for some reason, I don't know what was going on with her, but she would call me--like I'd be there on time, I'd be sitting in the waiting room and it was obvious there were a lot of people, 'cus they would talk about it and think it was real funny, who had been incarcerated and in jail. And maybe those</td>
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| 'cus they would talk about it and think it was real funny, that they had been incarcerated and, um, in jail. And maybe that's the only people she was supposed to be helping with the resume, 'cus, um, you know, she'd come out late for our appointment, she'd call me in and then she'd say, "Well, you know, uh, we only have so much time." And I said, "But I was here on time." And she goes, "Well, we only have five more minutes," and she said, "I really don't have time for this." And I thought, "Well who do you have time for then?"
| were the only people she was supposed to be helping with their resumes. She'd come out late for our appointment, she'd call me in and then she'd say, "Well, you know, we only have so much time." And I said, "But I was here on time." And she goes, "Well, we only have five more minutes," and she said, "I really don't have time for this." And I thought, "Well who do you have time for then?"
| Fearing Their Power | But I didn't say too much because you feel like they're in the power and they can do what they want if they so desire, I mean. No, I have at times with mental health. I felt like, well I don't want to end up in the hospital, so I better not say anything, you know, about this or that. And, um . . .
| But I didn't say too much because you feel like they're in the power and they can do what they want if they so desire. I feel like, well I don't want to end up in the hospital, so I better not say anything about this or that.
<p>| How Family Impacts Coping | Well--and this turned out horrible, but, um, it was--I was going through school and my mother was--was like at this point really going down hill. She was still at the house, 'cus I was able to keep her there and I was there, um, but she was very angry, very negative with me, as she always was--and that I was like dirt under her shoes, even though I was, as I was told by everyone else who saw the situation, I was the one keeping her able to be at home still. And I didn't realize how badly she was going downhill as far as emotionally and mentally. Um, my father had already died, um, and so at one point I must have said something about, &quot;Well, I feel like harming myself or I feel like sometimes my mother is just so nasty and horrible to me and I could just give her a little push or something.&quot; And--but I never, ever had or ever would have, but unfortunately I said that to someone and so then they felt | My father had already died. I was going through school and my mother was really going down hill. She was still at the house, 'cus I was able to keep her there, but she was very angry, very negative with me, like I was dirt under her shoes, even though I was, as I was told by everyone else who saw the situation, keeping her able to be at home still. And I didn't realize how badly she was going downhill emotionally and mentally. So at one point I must have said something to someone like, &quot;Well, I feel like harming myself or I feel like sometimes my mother is just so nasty and horrible to me and I could just give her a little push or something.&quot; But I never, ever had or ever would have, but unfortunately I said that to someone and so then they felt like they should bring in Senior Protective Services. I don't even like saying this, I'm sorry. I wish I hadn't said it. But, let's just put this to rest, this |</p>
<table>
<thead>
<tr>
<th>Traumatic Experience</th>
<th>and in fact my mother was the one that slapped me and--and used to, with my brother and I, with the stick--about--whacking us on the legs and stuff.</th>
<th>And in fact my mother was the one that slapped me and used to, with my brother and I, whack us on the legs and stuff with a stick.</th>
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<tr>
<td>How Family Impacts Coping</td>
<td>Right. And then my brother got into that kind of thing, um, when I asked him for some help, 'cus he was out of state and so was my sister. And my mother was--I was still trying to keep her at home.</td>
<td>Then I asked my brother for some help, 'cus he was out of state and so was my sister. And I was still trying to keep my mother at home.</td>
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<tr>
<td>How Family Impacts Coping</td>
<td>But at one point she tried, between the time I was still at school and I got home--and we had homemakers there and companions and stuff, but, um, the person had left and</td>
<td>We had homemakers there and companions and stuff, but at one point, the person had left and I hadn't gotten home yet, and my mother dragged a chair and was going to try to get up on the</td>
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my mother dragged a chair and, um, you know, was going to try to get up on the chair and fix something on a curtain. And I said, "Mom"--and then I get home and her leg is all bleeding and everything, 'cus she had thin skin and all.

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<tr>
<th>How Family Impacts Coping</th>
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<tr>
<td>So, I finally--I said to my brother, &quot;What are we gonna do? Wait until she--&quot; I said, &quot;her--her judgment is not--is off.&quot; And I said, &quot;Are we gonna wait until she breaks a hip or breaks something or worse.&quot; And--and so then, you know, he was all annoyed with me and how dare I ask him for help,</td>
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<tr>
<td>So I finally said to my brother, &quot;What are we gonna do? Her judgment is off. Are we gonna wait until she breaks a hip or something worse?&quot; So then he was all annoyed with me and how dare I ask him for help.</td>
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<th>How Family Impacts Coping</th>
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<td>so then he started in that, um--um, when I tried to say to the--the agency, well I need to take my mother to get her hair done or I need to take my mother to a doctor's appointment or something, so they--then I had my brother or my sister-in-law call me up and say--well, not my sister-in-law, she wouldn't, but she had my brother calling and saying, &quot;Well, where do you think you're taking</td>
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<tr>
<td>So next time I tried to say to the agency, &quot;Well, I need to take my mother to get her hair done&quot; or &quot;I need to take my mother to a doctor's appointment&quot; or something, then I had my brother or my sister-in-law call me up. Well, not my sister-in-law, she wouldn't, but she had my brother calling and saying, &quot;Well, where do you think you're taking her?&quot; And I said, &quot;What do</td>
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her?" And I said, "What do you mean?" And he goes, "Well, um, you have to get my okay or my wife's before you take Mom anywhere. And it should only really be to take her to, um, a doctor's appointment or to get her hair done." And--and finally after him doing that kind of stuff and then having people watching me or not watching me and what I was doing or not doing, I finally said to the people at that agency, "You tell her son to call his mother and tell her that. That she has to get his permission or her daughter-in-law's to go, um, out with me, uh, for whatever it is." Uh, so. It just became horrible.

I know, maybe I'm getting off on . . .

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<tr>
<th>Lack of Connection with Therapist</th>
<th>Yeah. No, this guy is not--is not, uh--I dunno what's going on, um, he's just--unless it's just that I'm more depressed now than--and I'm not finding any levity in--but some of the things that he's finding funny. I'm just am not finding funny. And I guess he's maybe just</th>
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<td></td>
<td>I dunno what's going on with this therapist, unless it's just that I'm more depressed and I'm not finding levity in anything, But some of the things that he's finding funny, I'm just not finding funny. I guess he's maybe just nervously laughing about something.</td>
</tr>
<tr>
<td><strong>Lack of Connection with Therapist</strong></td>
<td><strong>So it's not, um--and at one point I, um, was trying to do this thank you card design for, um, this woman and she had--we had started before my mother died, so it was like in maybe May or June that she asked me about doing it and so I had a design that I was gonna use and everything, but--um--and she wanted me to bill her before the end of June so that it would be that fiscal year. Um, but then I got behind on the card and so, for instance, you know, he was making fun of me about that--that instead of understanding that, okay my mother then died--and even though I had her in hospice at that point, I didn't expect her to die at that particular moment and day. Um, 'cus that weekend she had been--which was July 4th--she had been in--pretty well and still knew me and all that, so I hadn't expected her to--to die and,</strong> At one point, I was trying to do this thank you card design for this woman. We had started before my mother died, so it was like maybe May or June that she asked me about doing it and so I had a design that I was gonna use and everything, but she wanted me to bill her before the end of June so that it would be that fiscal year. But then I got behind on the card and so, for instance, the therapist was making fun of me about that, instead of understanding that my mother had died. Even though I had her in hospice at that point, I didn't expect her to die at that particular moment and day. 'Cus that weekend, which was July 4th, she had been pretty well and still knew me and all that, so I hadn't expected her to do. So the therapist was line, &quot;What do you mean? You got paid for it and now you're not doing it.&quot; And I</td>
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</table>
um. So he was kind of like, "What do you mean, you got paid for it and--and now you're not doing it." And I said, "Well, if I can't do it you can be sure I'll give her her money back." But, I said, "She wanted to be billed and," I said, "in fact, I've spoken with her and she's been very kind and very understanding and she said, 'You just take care of yourself. And promise me you will take care of yourself. And whenever you can get the card done, then you get the card done.'" [Tearful] And you can see that this is not helping me. It's really not helping me when I leave there and then I feel worse about not having gotten it done sooner.

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said, "Well, if I can't do it you can be sure I'll give her her money back. But, I said, "She wanted to be billed and in fact I've spoken with her and she's been very kind and very understanding and she said, 'You just take care of yourself. And promise me you will take care of yourself. And whenever you can get the card done, then you get the card done.'" And you can see that this is not helping me. It's really not helping me when I leave there and then I feel worse about not having gotten it done sooner.
Not Being Treated with Respect

Well, unfortunately or fortunately, uh, psychiatrists--I feel like sometimes they don't think before they talk, because, um, I don't know what it is with them--well now, they don't see you that often anyways, so they don't know a lot, but he seems to take more of an interest in what's going on than just prescribing the pills. But, recently I was talking to my therapist about it, and I said--you know here I'm talking to him about going on a different anti-depressant and he's saying to me, "Well, you're going to feel--one of the biggest things is you could feel, um, nauseous for at least two weeks or more." And I said, "Two weeks?" And he goes, "Well, uh, you know, uh, say you have twenty years to live, uh, two weeks out of twenty years is not a big thing." And I just kinda looked at him and he goes, "And besides--" he goes--and he gives this little grin, which he doesn't usually smile, and hegon I feel like psychiatrists sometimes don't think before they talk. I don't know what it is with them. Well, now they don't see you that often anyways, so they don't know a lot, but my psychiatrist seems to take more of an interest in what's going on than in just prescribing the pills. But, recently I was talking to my psychiatrist about going on a different anti-depressant and he's saying to me, "Well, you could feel nauseous for at least two weeks or more." And I said, "Two weeks?" And he goes, "Well, say you have twenty years to live. Two weeks out of twenty years is not a big thing." And I just kinda looked and him and he gives this little grin, which is weird because he doesn't usually smile, and he goes, "And besides, most of people can stand losing weight," he said. And I just kind of was like, "Yeah, if you had to take these psychiatric drugs, I don't think you would necessarily stay thin,
<table>
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<tr>
<th>Topic</th>
<th>Description</th>
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<tr>
<td>Not Being Treated with Respect</td>
<td>[The interactions with the therapist and the psychiatrist feel] [Sigh] Not very good.</td>
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<tr>
<td>Getting Support</td>
<td>Yeah. For a while, um, I really felt, um, you know, connected and seemed to be liked by a lot of people [at the Clubhouse]. And in fact I became like a volunteer leader and things like that, so, um, most of my experiences with the Clubhouse were good. [I left because] Well, because, um, I think I was going back to school . . . Most of my experiences with the Clubhouse were good. For a while, I really felt connected and seemed to be liked by a lot of people at the Clubhouse. And in fact I became like a volunteer leader. I think I left because I was going back to school.</td>
</tr>
<tr>
<td>Making Decisions About Care</td>
<td>Um, well, 2001. I'm thinking, yeah, yeah. So, um--and it just wasn't really meeting my needs anymore. Um, I hadn't gone back and, um, well I-- I don't like to put people in categories, It just wasn't really meeting my needs anymore. I don't like to put people in categories, but it seemed that is was more for less highly functioning people.</td>
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</table>
but it seemed that it was more for, um, well less highly functioning people. Um, kind of a place that they could go and--and be and--and, um . . .

<p>| Care that Feels Better | Right, yeah. Yes. Yeah, yeah. I think the Clubhouse was, um, helpful to me and--um--you know, I think clubhouses are helpful. But, it seems that now they're starting to get away from the old clubhouse model or whatever and, um, I think there still is a need for that and, uh, you know it's more now that they want to do, um, groups and not so much that they'll help you to go out to some nice things. Like, we used to do a lot of different things that I probably wouldn't have gotten to do and at that time you only had to pay five dollars and what they did was they kind of put that into a pool of money and so they would pay the rest, like if we went to a movie or something like that. So they made it very affordable and they don't do that now. It's one major outing that they do and they don't to the weekends like we used to do. Because a lot of people, I think, on the | I think the Clubhouse was helpful to me and I think clubhouses are helpful. But, it seems that now they're starting to get away from the old clubhouse model or whatever and I think there still is a need for that. Now it's more groups and not so much that they'll help you to go out to some nice things. Like, we used to do a lot of different things that I probably wouldn't have gotten to do and at that time you only had to pay five dollars and what they did was they kind of put that into a pool of money and so they would pay the rest, like if we went to a movie or something like that. So they made it very affordable and they don't do that now. It's one major outing that they do and they don't to the weekends like we used to do. Because a lot of people, I think, on the |
| Lack of Continuity with Care | Yes. Yup. Um, in fact I have some friends that we've discussed that. That it's too bad they don't have some kind of a graduation type, um, other group. But I guess they expect that you'll get together with those friends or whatever and do your own things and. But it might be, you know, a nice thing to have somebody that, um, that was a staff too, in case you wanted to bounce certain things off of them and stuff. | It's too bad they don't have some kind of a graduation group. But I guess they expect that you'll get together with those friends or whatever and do your own things. But it might be a nice thing to have somebody that was a staff too, in case you wanted to bounce certain things off of them and stuff. |
| Getting Support | I mean, I find having a resident advisor--um, I live in subsidized housing, but it's mostly for elderly. But there are a few of us that are, um, younger and disabled or whatever. And the resident advisor is a very kind person and so I feel less alone because I can go to her about different things that come up, you know, | I live in subsidized housing. It's mostly for elderly, but there are a few of us that are younger and disabled or whatever. And the resident advisor is a very kind person and so I feel less alone because I can go to her about different things that come up, financially or just housekeeping type things or whatever. |</p>
<table>
<thead>
<tr>
<th>My Experiences with Care</th>
<th>Financially or just, you know, um, housekeeping type things or whatever.</th>
<th>I don't know, I don't think so. I just hope I answered your questions though. Oh, sorry. No, no. Thank you. You've been very kind. Very kind. Okay. Okay.</th>
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<tbody>
<tr>
<td>My Experiences with Care</td>
<td>Oh, gosh. Um, probably like 19 [when I first entered care]. [Now I’m] 64.</td>
<td>I was probably 19 years old when I first entered care. I'm now 64 years old.</td>
</tr>
<tr>
<td>My Experiences with Care</td>
<td>Um. Well, first I was in private care, um, then I was, uh--there was a hospital. I was at that hospital a couple of times. And then the clinic now. But before then I had been in kind of the private sector. So, um, uh, for the last, um, at least 10 years I guess, I've been at a clinic. A hospital.</td>
<td>I was first in private care, then I was in a hospital. I was at that hospital a couple of times. And now I'm at the clinic. But before then I had been in private care. For at least the past 10 years I've been at a clinic.</td>
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Appendix H: Participant Themes

Participant 1: Thomas

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<tr>
<th>Broad Themes</th>
<th>Specific Themes</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Proving Myself to Others</td>
<td>Proving Myself to Others</td>
<td>&quot;The director of the Clubhouse was one of the people who had been at the partial hospital program. So, I had to sort of prove to this person that I was ready to go back to work.&quot;</td>
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<tr>
<td>Transitioning from Patient to Employee</td>
<td>Transitioning from Patient to Employee</td>
<td>&quot;The staff aren't so patient with me, but with the other clients they are. The staff expect more out of me, because I'm an employee.&quot;</td>
</tr>
<tr>
<td>Belonging and Responsibility</td>
<td>Belonging and Responsibility</td>
<td>&quot;I'm deeply involved in my church community and also in a local mental health advocacy organization. So, that was really good and that gave me a lot of confidence, too.&quot;</td>
</tr>
<tr>
<td>Having Responsibility and Doing Good Work</td>
<td>Doing a Good Job</td>
<td>&quot;They do a yearly evaluation of me and my evaluation was near the top, like most of my marks were the highest possible. I feel good, I feel like I'm doing a good job.&quot;</td>
</tr>
<tr>
<td>Independence and Functioning</td>
<td>Independence and Functioning</td>
<td>&quot;I went back to school and got a culinary arts certificate and got involved with cooking and I found that the work was not only financially lucrative, but it also helped me in terms of my symptoms, keeping busy and not thinking about my problems so much.&quot;</td>
</tr>
<tr>
<td>Being Self-Sufficient, But Needing Support</td>
<td>Self Sufficiency vs. Needing Support</td>
<td>&quot;I think that I don't need as much outside support as I did in the past. It feels sort of good, in a way, to be self-sufficient. But at the same time, I think that once in a while I might run into a problem that I can't&quot;</td>
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<tr>
<td>Experience</td>
<td>Support</td>
<td>Response</td>
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<tr>
<td>Work-Readiness rather than Emotional Support</td>
<td>Work-Readiness rather than Emotional Support</td>
<td>&quot;However, I do feel somewhat limited by my disability. I'd prefer that maybe the staff not be so judgmental or critical when I make a mistake. But, at the same time, I think they're trying to create an environment where you experience what you would in the community, if you had a job out there.&quot;</td>
</tr>
<tr>
<td>Experiencing a Lack of Support</td>
<td>Lack of Support</td>
<td>&quot;I used to have a therapist, but now there isn't really anybody I could talk to in depth about personal problems. I stopped seeing the therapist about 15 years ago. For the most part, I'm okay with it.&quot;</td>
</tr>
<tr>
<td>Fear for the Future</td>
<td>Fear for the Future</td>
<td>&quot;When my parents pass away, it's going to be a shock and a big change. I don't know how I'm going to handle it. I could have a relapse. It causes me a great deal of anxiety.&quot;</td>
</tr>
<tr>
<td>Planning for the Future</td>
<td>Planning for the Future</td>
<td>&quot;What I'd like to do is plan the estate so that I can keep the inheritance and keep my entitlements. There's a law firm for seniors and the disabled and they have people that do estate planning. If I could get connected with them I think they could probably help me manage my finances and also advise me in times where I might come into some sort of legal trouble or something. That happens a lot with disabled persons, they get into all kind of legal problems.&quot;</td>
</tr>
<tr>
<td>Getting Involved with Cooking</td>
<td>Getting Involved with Cooking</td>
<td>&quot;One of the chores was being assigned to the culinary unit at the partial hospital program. That's where I first got involved with cooking.&quot;</td>
</tr>
<tr>
<td>Support in the Past</td>
<td>Support in the Past</td>
<td>&quot;The case manager I had in the past set me up with my entitlements and would make recommendations for services, like a good dentist that took Medicaid.&quot;</td>
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<tr>
<td>The Hospital was a Dark Time</td>
<td>The Hospital was a Dark Time</td>
<td>It was kind of a dark time for me, the partial hospital. It was rough. We did chores there, which I guess were probably designed to help you in your recovery, but it was difficult.</td>
</tr>
<tr>
<td>The Hospital is a Place to Recuperate</td>
<td>The Hospital</td>
<td>&quot;I started in the partial hospital program. They had a psychiatrist there and he would prescribe medication and then I would go to what are called &quot;groups,&quot; which are activities, within the building. The partial hospital program was a place where you're kind of recuperating.&quot;</td>
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<tr>
<td>Staff are Dictatorial Across Settings</td>
<td>Staff are the Same</td>
<td>&quot;The staff at the partial hospital program and at the Clubhouse are very similar in the way that they approach things. They know how to talk to people with disabilities.&quot;</td>
</tr>
<tr>
<td>Staff are Dictatorial Across Settings</td>
<td>Staff are Different and the Same</td>
<td>&quot;I think that the staff at the Clubhouse are better suited to the Clubhouse and the people at the partial hospital, some of them were not well suited for working in mental health treatment. They weren't sensitive to the clients. At the Clubhouse, they're more sensitive to our needs and so forth. Although, in both places there is kind of a dictatorial side to it.&quot;</td>
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<tr>
<td>Staff are Dictatorial Across Settings</td>
<td>Manager-Types</td>
<td>&quot;The current director is sort of like that too, but in a different way. She's a &quot;manager-type.&quot; They were both &quot;manager-types.&quot; The current director...&quot;</td>
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<td>Topic</td>
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<td>Quote</td>
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<td>----------------------------------------------------------------------</td>
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<tr>
<td>Wide Range of Recovery</td>
<td>Wide Range of Recovery</td>
<td>&quot;There's a wide range of people in recovery at the Clubhouse. Some of them are more debilitated and some of them actually went back to work.&quot;</td>
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<tr>
<td>Being Led versus Leading</td>
<td>Being Directed and Not</td>
<td>&quot;The director of the Clubhouse who had come from the partial hospital program has retired now, so there's a new director. The former director was geared toward the rehabilitation model whereas the new director is definitely recovery model-oriented. The old director was the sort of person who likes to be very much involved in running things and directing people. The new director more just sits back and lets you take over. She relies on my supervisor if I have any problems or questions.&quot;</td>
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<tr>
<td>Being Made to Feel Small and Being Disregarded</td>
<td>Being Made to Feel Small</td>
<td>&quot;The two directors had very different personalities. The personality of the first director was more dictatorial. She was more emotional, sort of hot tempered, and she could get very angry. She had a way of making me very uncomfortable when I did something wrong. She would raise her voice and she had an angry tone. She just had a way of making me feel small, I guess you could say.&quot;</td>
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<tr>
<td>Clients Being Disciplined</td>
<td>Rules and Consequences</td>
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<td>&quot;In the past, they had a system where if you broke a certain rule, then there was a certain consequence. The first consequence might be suspension for a day, and then maybe it would be a week or a month, and then the final consequence would be permanent suspension from the program.&quot;</td>
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<thead>
<tr>
<th>Being Made to Feel Small and Being Disregarded</th>
<th>Being Disregarded</th>
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<td>&quot;The psychiatrist at the partial hospital program came from the prison system; he was very stern and he had a bad temper. So, it was hard working with him. One of the things that came up when I was in the partial hospital program was that they put me on some medications that didn't agree with me. When I asked to be changed to something else, they didn't listen to what I said. They disregarded my input and so I struggled for a long time with side effects from the medication.&quot;</td>
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<tr>
<th>Clients Being Disciplined</th>
<th>Clients Need Authority</th>
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<tr>
<td>&quot;We have people at the Clubhouse that do things they aren't supposed to. For example, there's a designated smoking area and sometimes they won't use it and they'll throw their cigarette butts on the ground. So the director will have to say, &quot;Well, you know, if you throw your cigarette butts on the floor or near the building, the building could catch fire.&quot; Some of the people have to be told, because there's a wide spectrum of people in different place in their recovery. And they have to sort of disciplined somewhat.&quot;</td>
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Being Advised Instead of Punished

"They did that for a while, but then a recent development is a new system where the person would have somebody counsel them about the problem and they're shown ways that they could do things differently so that they wouldn't cause problems. I don't know how it will work yet, because they just changed over to the new system."

Being Advised Instead of Punished

"I have a feeling, just a hunch, that the fact that there isn't a punishment for their behavior, will make some people more comfortable. Instead of a punishment, they are actually advised as to what to do."

Staff Need to Provide Support and be Patient

"So staff at the Clubhouse have to be able to handle that type of client. They have to be able to direct them and help them, show them what to do. And they also have to have a patient side; when they're trying to teach something to a client, they have to be very patient with them and work with them, supervise them and show them what to do. Staff at the Clubhouse are able to be patient with clients when they need to be."

Being Listened To

"The psychiatric nurse I see now listens very carefully to what I say, and luckily the medication seems to agree with me."

Having a Sense of Stability and Security

"I feel like I have a marketable skill as a chef. So, I feel like if something happened or for some reason the program closed or if I was laid off, that I could get work as a cook. So
| The Importance of a Safe Place | In a Safe Place | there's a sense of stability and security."
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<td>&quot;I feel like I'm in a safe place where I am. I feel more secure at the Clubhouse. I think that if I were to leave that environment and go out into the community, I might be treated in the same way where I was before, where I was put down. Or maybe, if I was in a situation where I was having some kind of psychotic symptom, people might not understand what's going on and there might be some kind of serious consequence to that.&quot;</td>
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</tbody>
</table>

| The Importance of a Safe Place | The Safety of Disclosing | "I like the people that I work with there. I did have some trouble when I was working outside of the Clubhouse. Some people, when I disclosed my illness to them, abused me. People, for some reason, put me down, because I had a disability. The Clubhouse is a very safe place. For the most part, people understand where you're coming from." |

<p>| Limited by My Disability | Limited by My Disability | &quot;I do get a sense from the staff at the Clubhouse that my disability does limit my work ability somewhat. I feel like I'm running up against limitations, in terms of remembering things. So, I have to try to write everything down because when they give me a lot of information, sometimes I can't remember it all and then sometimes I will forget that I had to do certain things. So, when that happens, sometimes I get criticized.&quot; |</p>
<table>
<thead>
<tr>
<th>My Confidence Comes from Myself</th>
<th>My Confidence Comes from Myself</th>
<th>&quot;I think that my confidence comes from within myself. I don't think that the program gave me confidence so much, but I think that the program gave me stability.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanting to Provide Better Food</td>
<td>Wanting to do More</td>
<td>&quot;I feel like the meals that I'm preparing are not really the healthiest meals, and I feel that what you take into your body has a lot to do with how much you recover. We don't get as many fresh vegetables as I would like and I have to really cut a lot of corners when I'm preparing the lunch. So, I feel like I'm feeding them, but at the same time I feel guilty that I'm not feeding them the way I would like them to be fed.&quot;</td>
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</table>
**Participant 2: Leah**

<table>
<thead>
<tr>
<th>Broad Themes</th>
<th>Specific Themes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being Respected and Giving Input</td>
<td>A Good Therapy Relationship</td>
<td>&quot;I will say, I went to therapy not knowing if it was gonna be a good match. It absolutely is. It's just a joy . . . She and I are just on the same page . . . So it's just so fun and she's so non-labeling. I don't even see the DSM sitting around her office, which I like.&quot;</td>
</tr>
<tr>
<td>Being Respected and Giving Input</td>
<td>A Good Doctor</td>
<td>&quot;I only see the psychiatrist about every three months. I can always call her, but I'm not dependent on her in any way. We just get along well and I respect her and she respects me. She let's me guide how things are going to go.&quot;</td>
</tr>
<tr>
<td>Being Respected and Giving Input</td>
<td>My Own Input</td>
<td>&quot;I've been in treatment, on and off, since I was 14. The care that I receive now compared to the care I've received in the past is like day and night. The kindness and letting me have my own input. I'm still on a little bit of medication, but I discuss it with the psychiatrist and she says, 'Well, what do you think?' We talk and she let's me give input.&quot;</td>
</tr>
<tr>
<td>Treatment Varied, but Started to Improve</td>
<td>Treatment Began to Get Better</td>
<td>&quot;I was in and out of a city hospital. I'll just say it was a nice unit. It was certainly way better.&quot;</td>
</tr>
<tr>
<td>Treatment Varied, but Started to Improve</td>
<td>Treatment Varied</td>
<td>&quot;Treatment varied, it varied, but the system was starting to improve.&quot;</td>
</tr>
<tr>
<td>Sources of Support</td>
<td>Support</td>
<td>&quot;I did have a therapist at the time, thank God almighty it was a woman, and she knew the psychiatrist. She supported me and I got support at work as well.&quot;</td>
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<tr>
<td>Sources of Support</td>
<td>Early Support</td>
<td>&quot;When I was 14, my mother finally picked up that something was wrong and linked me with a psychiatrist. The psychiatrist was really my only friend.&quot;</td>
</tr>
<tr>
<td>Sources of Support</td>
<td>Very Good Support</td>
<td>&quot;I've had four joint replacements and I was having terrible pain after the most recent knee replacement. I had very good support at work; they allowed me to work from home when I got better enough and allowed me to adapt my schedule.&quot;</td>
</tr>
<tr>
<td>Sources of Support</td>
<td>A Good Partner</td>
<td>I said to my partner, who's very low-keyed about the whole thing, I said, 'Honey, do you think I should go see somebody?' He'd never said yes before, but this time he said, 'Yeah, I think so.' He's wonderful. &quot;</td>
</tr>
<tr>
<td>Beginning to Thrive Again</td>
<td>Doing Pretty Darn Well</td>
<td>&quot;After we moved in with my aunt and uncle, I wasn't in treatment. I was doing pretty darn well.&quot;</td>
</tr>
<tr>
<td>Beginning to Thrive Again</td>
<td>Beginning to Thrive</td>
<td>&quot;I was beginning to thrive when I got hired at a local mental health advocacy organization.&quot;</td>
</tr>
<tr>
<td>Beginning to Thrive Again</td>
<td>Trying to Work</td>
<td>&quot;Finally, I got to the point that I wanted to try to work.&quot;</td>
</tr>
<tr>
<td>I Take Great Pride</td>
<td>My Strengths</td>
<td>I have a background in oral history, writing, literature, and social service work.</td>
</tr>
</tbody>
</table>
I Take Great Pride

I happened to be in a DBT program at the hospital the psychiatrist worked at, because I was starting to slide, but I wasn't identifying exactly what was going on. When I went in for the intake, I said, "Somebody on staff is abusing me. And he's diverting meds." I thought they were just going to gloss over it. The next time I came in, a bigwig, the Director of Medicine or something, was there. He said, "Tell me. Right now. Tell me what is going on." I told him.

Taking Action

"I take great pride in the fact that I spoke out. I've been sexually abused many times. First, I feel compassion, "Oh, I want him to get help." Oh right. And then I changed my mind real fast. It's like, okay, I ain't gonna take this from this jerk."

I Take Great Pride

I walked into his office and I stood there proud and tall, and I said, "You have done harm." You know, the Hippocratic oath. And I said, "Dr. So-and-so knows and he knows that you've been taking those medications and diverting them for yourself. And Dr. So-and-so is going to be speaking with you." He blanched and leaned back in his chair and said, "I'm sure he is." I said, "I never want to see you again or talk to you. I am done and I'm outta here." And I walked out.

I Take Great Pride

I Stood Proud and Tall
<table>
<thead>
<tr>
<th>I Take Great Pride</th>
<th>I was an Activist</th>
<th>&quot;I began my senior year of high school and I did pretty darn well. I got involved in the civil rights movement. This was in 1964, so it was right before the Civil Rights Act got passed. And, I mean, I was really an activist.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Take Great Pride</td>
<td>I was Savvy</td>
<td>&quot;So I said, the hell with this. I am not staying here. I got a Kotex pad and I put a little nick in my arm, somehow, with something, and I put the blood on the pad. I was savvy; I dunno how I even thought of that. And you know what they did? They took me out. They put me on a regular unit&quot;</td>
</tr>
<tr>
<td>No Support, Just Horror</td>
<td>No Support, Just Horror</td>
<td>&quot;I don't remember any interaction with the people who worked there. All I did was sit in my room. I mean, I suppose I got food and stuff, but I don't remember that part. I just remember the horror of it.&quot;</td>
</tr>
<tr>
<td>No Support, Just Horror</td>
<td>Horrific</td>
<td>&quot;It was so institutionalized, it was horrific. The beds were so close. People were hallucinating and crying and sobbing all night. We wandered around the day room, you know, the stereotypical wandering around the day room. People could smoke, so there's a little thing on the wall so they could light their cigarettes. There's no place to sit. There's one or two couches that everybody's vying for. I got shock treatments with no freaking anesthesia. There was one person, or perhaps two, that&quot;</td>
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<tr>
<td>No Support, Just Horror</td>
<td>A Psych Unit</td>
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<td>were kind. Everybody else was just horrible.&quot;</td>
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<td>&quot;So here I was, in this ancient city hospital. I'm eight months pregnant on a psych unit. This was in the 1960s, so there was this long, dark hallway. There were nuns who were patients there, sitting on the edges of their bed. And here I am, knowing I'm going to lose my child... So they put me in this hellhole. I was hysterical. All I did was cry. It was just god-awful.&quot;</td>
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<tr>
<th>Trauma</th>
<th>God-Awful Reflection</th>
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<tbody>
<tr>
<td>After a time, I became fully aware of what was happening. I did a lot of god-awful reflection and &quot;what the hell do I do&quot; and &quot;who do I turn to.&quot; I went to visit my family and spent most of the time holed up in my room crying. They didn't know exactly what was I was doing, they thought I was just reading or something. I mulled it over a lot and I got enraged. I said, &quot;This is really, really bad.&quot;</td>
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<table>
<thead>
<tr>
<th>Trauma</th>
<th>A Nightmare</th>
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<tbody>
<tr>
<td>&quot;And then my family got uprooted from the state where we'd been living and we went back to the city where I was born. My father had mental health issues too and he was hospitalized and ended up in the state hospital. It was a nightmare. My family fell apart and we left in the middle of the night, my mother, sister, and I. We left the house, my dog, everything I owned, and...&quot;</td>
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<tr>
<td>Trauma</td>
<td>Trauma</td>
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<tr>
<td>&quot;As I said, I've had multiple, multiple, multiple, uncountable traumas in my life. Sexual traumas, losses, hospitalizations and treatments that were not good, and I've been in two fires. I just keep running up against the trauma. I seem to get over it and then something else comes up in my face and brings it up. I have screaming nightmares.&quot;</td>
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<tr>
<td>Trauma</td>
<td>Raped</td>
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<tr>
<td>&quot;I got raped by my first boyfriend, when I was 14. And, I mean, he's my boyfriend, right. Raped. I've had a history of several raped. Nothing in the family, but rapes, rapes, and more rapes.&quot;</td>
<td></td>
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<tr>
<td>Trauma</td>
<td>A Nightmare Scene</td>
</tr>
<tr>
<td>&quot;I sued the psychiatrist and it got settled out of court. It was a nightmare scene. I had to go multiple times to be interviewed by a forensic psychiatrist and it was god-awful, but I survived. Talk about abuse by the system, there we go. It was about as bad as you can get.&quot;</td>
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<tr>
<td>Trauma</td>
<td>Cried Myself to Sleep</td>
</tr>
<tr>
<td>&quot;But, my husband turned out to be a severe abuser of alcohol. I had no clue until our honeymoon. The second night, he got flat out drunk with scotch and I cried myself to sleep.&quot;</td>
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<tr>
<td>The Bad Doctor</td>
<td>The Bad Doctor</td>
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<tr>
<td>Finding Help</td>
<td>Finding Help</td>
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<tr>
<td>I Just Couldn't Function</td>
<td>To the State Hospital</td>
</tr>
<tr>
<td>I Just Couldn't Function</td>
<td>A Raw Mess</td>
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</table>
| I Just Couldn't Function | Inside Myself | "I had no clothes, you know. I had the history behind me and there was a time period where I didn't even talk. I mean, I might have said a
<table>
<thead>
<tr>
<th>I Just Couldn't Function</th>
<th>I Just Couldn't Function</th>
<th>&quot;After that, I just couldn't function. I ended up just staying home and sitting on the couch.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Zombie</td>
<td>A Zombie</td>
<td>&quot;Before, I was a frikking over-medicated zombie. I was obese. When I started volunteering at the advocacy organization, I was a zombie. I could barely speak because my mouth was dry, dry, dry.&quot;</td>
</tr>
<tr>
<td>Loss</td>
<td>My Baby</td>
<td>&quot;When I got pregnant with my daughter, I went to all these different places, first here and then out of state, and then ultimately to a home for unwed mothers. And I realized that they weren't going to let me keep my baby. Nobody was offering supports. So, I threatened suicide. I wasn't going to give my baby up, no way.&quot;</td>
</tr>
<tr>
<td>Loss</td>
<td>I Lost Her</td>
<td>&quot;I took care of her in the hospital and I held her. They kept you for like four or five days then. Then I had to surrender my little girl. I lost her. I found her later, but that's a whole other story.&quot;</td>
</tr>
<tr>
<td>Things Turned Around</td>
<td>My Children</td>
<td>&quot;I ended up getting married and things turned around. Everything was great. I was happy. I still didn't have my first child, my daughter, but I had my first son and then my third child.&quot;</td>
</tr>
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### Participant 3: Dinah

<table>
<thead>
<tr>
<th>Broader Themes</th>
<th>Specific Themes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receiving Services at LMHA</td>
<td>Treatment Location</td>
<td>&quot;Both my previous therapist and my current psychiatrist were at the same agency. The site is a local mental health or behavioral health care service that reaches a lot of regions. I don't know if I would call them a Local Mental Health Authority, but they are that far reaching and they're funded in part by the Department of Mental Health and Addiction Services.&quot;</td>
</tr>
<tr>
<td>Choosing Not to be in Therapy</td>
<td>Current Treatment</td>
<td>&quot;It's something that I may pursue again, but I spent a long time in therapy already. So, for the moment I just see a psychiatrist for medication management.&quot;</td>
</tr>
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</table>
### The Kind of Work I'm Able to Do in Therapy

**My Last Therapist**

“And then I started seeing the third therapist. It was originally to talk about weight issues and, you know, why I keep doing the same things that are bad for me in terms of diet, nutrition, exercise, that kind of stuff. I just wanted to talk about the practical stuff that was impacting my self-esteem. So, originally it was that and then we were able to delve into some other issues. I'm in a care giving role in terms of taking care of an elderly parent, you know, a lesbian woman involved in a bi-racial relationship, so we were dealing with things and talking about those kinds of issues.”

### How Therapy Changed Over the Course of Recovery

**My First Therapist**

“The first therapist I had at the agency was the one I saw for the longest time. I started out seeing her in the mobile crisis unit, so she would come out to my house and we would meet outside in the community and things like that. At Dunkin Donuts or wherever. And then, when I recovered enough to not be in the mobile crisis unit, she transferred me to adult outpatient therapy and saw me there for a long time.”

### Differences in Therapists' Approach and Ability to Listen

**Differences in Therapists**

“There's a difference in approach in terms of the way they worked with clients and the way they transferred the knowledge that they had and listened.”

as clients. We have to give them the questions when they don't have them.”
<table>
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<tr>
<th>Using Social Supports</th>
<th>Using Social Supports</th>
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<tr>
<td>“I know that there are times in my life when I do wish I had someone to talk to like that. But really, I was probably under utilizing the outpatient therapy. At this point, I consult my friends if I want to talk about something.”</td>
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<tr>
<td>Mutual Growth in Therapy</td>
<td>Mutual Growth</td>
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<tr>
<td>“But really, the benefit of sharing information is that my therapists treat me better as a result and I also learn from them, ‘cus I don't know everything.”</td>
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<tr>
<td>Therapeutic Connection</td>
<td>Therapeutic Connection</td>
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<tr>
<td>“And there are some people who, like me, have a standoffish attitude toward people. But, just the way she carried herself made it comfortable, made me feel comfortable.”</td>
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<tr>
<td>Lack of Therapeutic Connection</td>
<td>Lack of Therapeutic Connection</td>
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<tr>
<td>“I'm not sure why I left my second therapist. I can't remember. It could have been a combination of reasons; we weren't working well together, or she changed the hours, or I wasn't going regularly, or was not engaged with her, not connecting. She called me psychotic once and I was like, ‘Okay, then.’ We had seen each other for a long time, we just weren't connecting. So, I stopped going to therapy for a long time.”</td>
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<tr>
<td>Negotiating the Place Between Client and Professional</td>
<td>Negotiating the Place Between Client and Professional</td>
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<tr>
<td>“At this point in my life, I would probably look for a therapist outside of the agency mainly because I might be looking for a job within the agency.”</td>
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<tr>
<td>Being Supported in Professional Goals</td>
<td>Being Supported in Professional Goals</td>
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<tr>
<td>Pursuing a Career</td>
<td>Career Development</td>
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<tr>
<td>What Propels me Forward</td>
<td>What Propels me Forward</td>
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<tr>
<td>Difficult Transitions Between Therapists</td>
<td>Difficult Transitions</td>
</tr>
<tr>
<td>My Process of Recovery</td>
<td>Process of Recovery</td>
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<td>------------------------</td>
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<td>agency she went to and she wasn't at liberty to tell me where she was going. So, yeah, it was difficult.”</td>
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<thead>
<tr>
<th>Discovering the Behavioral Healthcare Community and Growing as an Advocate</th>
<th>Growth as a Professional and Advocate</th>
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<tbody>
<tr>
<td>“Yeah, I mean, she saw me through and worked through some of the darkest days. Like, early in recovery. I mean, I wouldn't even consider myself in recovery at the time she was seeing me. I was paranoid, I had a very low self-esteem just because I was coping with a mental health diagnosis in the first place and she lived that through with me and saw me progress to the point where she said, ‘I cannot keep you as a client anymore. You have to move on from here. You're not in crisis at this point.’”</td>
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<tr>
<th>Discovering the Behavioral Healthcare Community and Growing as an Advocate</th>
<th>Discovering the Behavioral Healthcare Community</th>
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<tr>
<td>“I'm involved with the Hearing Voices Network and we brought this to the state through someone who worked for the Department of Mental Health and Addiction Services. We started out with six groups and now we have 14 groups.”</td>
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<thead>
<tr>
<th>Discovering the Behavioral Healthcare Community and Growing as an Advocate</th>
<th>Discovering the Behavioral Healthcare Community</th>
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<tbody>
<tr>
<td>&quot;So, before I even began working as a volunteer, I was a student enrolled in their advocacy education course and it was my introduction into the behavioral healthcare community in this state. I didn't know a behavioral healthcare community existed. It was probably five years into my diagnosis, my formal diagnosis, as</td>
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<tr>
<td>Mental Health Care has Changed, but the Status Quo is Hard to Change</td>
<td>Changes in Mental Health Care</td>
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<tr>
<td>Mental Health Care has Changed, but the Status Quo is Hard to Change</td>
<td>Changes in Mental Health Care</td>
</tr>
<tr>
<td>Mental Health Care has Changed, but the Status Quo is Hard to Change</td>
<td>We Still Have a Long Way to Go</td>
</tr>
</tbody>
</table>
| Treatment that feels Human | Treatment that feels Human | "And if it wasn't for the occupational therapist on that unit, I would really have lost faith in humanity. It was the other patients in the unit and the occupational therapist that actually helped me with washing my clothes after I
agreed to take their medication to get out of restraints. So, she actually treated me like I was a human being, regardless of her job, you know. It was like she went above and beyond to be kind."

"But, I feel like my psychiatrist, at least, is getting it and he understands. He's not certain what the outcome will be with me, but at least he's willing to work with me . . . I've seen this psychiatrist since 2006, maybe 2005 or something, he's been my psychiatrist for all this time. And so he's seen my growth and development as a human being and as a professional and I think that has probably made a difference for him. You can't be in behavioral health in this state without knowing that recovery is possible, I don't think. Is it possible to not know that? It's real for people."

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Treatment that is Unwarranted, Dehumanizing, and Traumatic
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Unwarranted Treatment
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“And when I say that I didn't do anything to warrant those restraints, I mean that. Who does anything to warrant that? . . . I wasn't, like, escalated. People restrained me in order to get me to take medication or because . . . I had gone into a patient's room in a distressed moment. I was having an experience where I was having a dream . . . where I felt like my brother was talking to me and I went into the patient's room
and I rubbed his head and I called him my brother’s name and that was it. But evidently, I didn't have on any clothes at the time and had been going through something. But I wasn't a danger to the patient and I didn't do anything that was violent. They asked me to go back to my room and I was, like, still probably in a malaise or something and didn't want them to tell me to go back to my room or something. But it didn't warrant eight people throwing me down on a gurney and restraining me for a night, or whatever. Yeah, it was crazy.”

“Treatment that is Unwarranted, Dehumanizing, and Traumatic

Dehumanizing Treatment

“I like to think I'm a loving person, I haven't done everything perfect in my life by any means and so I don't want to portray myself as a perfect human being, we're all imperfect. I think none of us, there's not a single solitary soul, that I feel deserves to be placed in four point restraint.”

“Both experiences were pretty traumatizing. When I was a child, I was molested and no one listened to me. I didn't tell about the experience. So, when I was restrained, it felt like my body wasn't my own and no one was available to hear me or that they didn't care how I felt. It felt punitive, not like it was healthcare.”
<table>
<thead>
<tr>
<th>Disrespecting Clients</th>
<th>Disrespecting Clients</th>
<th>&quot;that is disrespectful, I think, to call someone psychotic when that's not a word I use to refer to myself under any circumstance.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment is Based on Appearance</td>
<td>Treatment Based on Appearance</td>
<td>“At the time I was restrained, my hair was in locks, you know, I might have looked bigger, I weighed more, I'm not saying there's a difference, but I'm saying there's a difference in how you're treated. And I would say I was restrained by at least seven or eight people, most of them were men.”</td>
</tr>
</tbody>
</table>
| Treatment is Based on Appearance | The Price of Freedom | “So, going through that experience I learned that there's a certain way a patient has to talk in order to be heard and in order to have what we desire to have. And so what I did was agree to take the medicine so that they would let me out of that facility at some point. So, the next week I started a medication regimen and was discharged on my birthday a week later. It was February of 1999 when they let me out. And then I went and I saw a doctor and learned quickly that when you go through the many mental status exams that there are certain ways you have to answer those questions and there's certain ways you have to look in order to for the providers to view you a certain way. And all the talk was about being med compliant, being treatment compliant, and it really is pathetic, but that's what I
<p>| Desires About Medication Aren't Respected | Desires not being Respected | “The doctor at the hospital, she wanted me to take medicine and so that was her goal, for me to take medicine in order to get out. I mean, she didn't say, ‘Okay, well, let's look at some alternative ways for you to heal.’ For her, medication was the answer. And talk about cultural competency and respecting somebody's desires not to take a pill, not to take a chemical!” |
| Desires About Medication Aren't Respected | Being Forced to take Medication | “I initially took medication to get out of the facilities and then to satisfy my family, who, like I said, believed that you should take medicine if you have a mental illness. But it's also been my own doing and I take full responsibility for continuing to take the medication even though I feel some kind of way about it and don't think it's effective. It has never stopped the voices that I hear.” |
| The Impact of Choosing to take Medication | Deciding to take Medication | “I was given Haldol when I was restrained and the next day I actually did feel better, calmer. And one of my friends came to visit me and I said, ‘What happened?’ Or ‘Why am I feeling so much calmer?’ Or this, that, and the other thing. And he said, ‘You were medicated.’ And I said, ‘Oh, is that the impact of medication?’ And he said, ‘Yes.’ I said, ‘Maybe I should take it to get out.’” |</p>
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<tr>
<th>The Impact of Choosing to take Medication</th>
<th>The Impact of Choosing to take Medication</th>
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<td>“Really, psychiatry has had an impact on my life in a very detrimental way, I will say. But, also there's been some positives. I try to stay positive. It's not all bleak and there's certainly nothing I can do about it because the past is gone. It's gone. I lost those years and, you know, I've done other things I don't like. Like I said, I'm not perfect.”</td>
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<tr>
<th>The Impact of Hearing Voices</th>
<th>Hearing Voices</th>
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<tr>
<td>“But, it surprises me, I have to say, that other people don't hear the voices. When people said, ‘No, I don't hear them,’ you know, I was like, ‘You gotta be kidding!’ But, how can you not be surprised? Because they're always with me, 24/7.”</td>
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<tr>
<th>The Impact of Hearing Voices</th>
<th>The Emotional Impact of the Voices</th>
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<tr>
<td>“I used to take anxiety medication because I experienced anxiety and social phobia. I couldn't be in public, period. I couldn't go to grocery stores, I couldn't do events. Prior to that, I was teaching in front of groups of people, that's my role now in the job. But I couldn't be in public places, I couldn't facilitate support groups where there were people talking because of my experiences with the voices and how they make me cringe sometimes and feel out of sorts. I couldn't do it. But I've recovered and now I can do it.”</td>
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<tr>
<td>Topic</td>
<td>Author's Response</td>
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<tr>
<td>Agreeing to Seek Treatment</td>
<td>“Prior to that, I was asked to take a leave of absence from work because I snapped at one of our students who asked me something personal. Probably, my boss was like, ‘You need to take care of yourself. You need to get some rest and see somebody.’ She was of the mindset that I needed to do that and I agreed with her.”</td>
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<tr>
<td>Anger About Mental Health Care Experiences</td>
<td>“I'm angry that that happened to me. I continue to be angry that that happened to me. But, I know that I'm not alone, so I'm angry that it's happened to anybody.”</td>
</tr>
<tr>
<td>Feeling Unable to Advocate for Self</td>
<td>&quot;one of the things that I don't do is self-advocate very well. I teach it to other people. You know, it's one thing to teach it, it's another thing to practice it. But, that's the kind of advocacy we teach: self systems and legislative . . . You have to speak up for yourself, I know, but there's something that prevents me from speaking up and it's probably because stuff like that hurt me deeply, like being called a name, hurts me so deep, like to my core, that I don't always have the words to combat it.&quot;</td>
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<tr>
<td>Rights Not Being Communicated</td>
<td>&quot;It wasn't like the stuff I learned later about patients' rights being posted and having to know that you have the right to refuse. I thought I had been committed to this hospital and later realized that I had signed paperwork so it was voluntary the whole time&quot;</td>
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<tr>
<td>My Rights were Obliterated</td>
<td>Learning about Rights</td>
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<td>&quot;What happened to me and what I later learned when I moved back to this state about the patients' bill of rights is something that was obliterated. My rights were obliterated. No one told me, I didn't know. I really was shocked that I was even admitted to the hospital in the first place.&quot;</td>
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<thead>
<tr>
<th>Dealing with Trauma Experienced in Mental Health Care</th>
<th>Freeing Yourself Within</th>
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<tr>
<td>&quot;And the only thing I could tell you is thank god I had practice in my undergraduate life with transcendental meditation and yoga, because the only way to deal with four point or two point restraint is to go inward, to try to calm yourself. Because what happened is... my blood pressure went through the roof and I'm in these restraints and you can't move and you can't scratch or whatever, you can't do anything. You can only free yourself within and so that's what I did in order to get through the experience until they removed the restraints.&quot;</td>
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<tr>
<th>Family Involvement in Treatment</th>
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<tr>
<td>&quot;I also had family member that weren't advised of my rights or of their rights as family members. I had people who would just say, ‘Take your medicine, take your medicine, take your medicine’ in my family, so my boundaries with them and healing those relationships is taking some time because I still never forget, although I forgave them for their role, because they had a lack of information.&quot;</td>
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<tr>
<td>Keeping Experiences Private</td>
<td>Keeping Experiences Private</td>
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Participant 4: Dolores

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<tr>
<th>Broader Themes</th>
<th>Specific Themes</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Choosing What Care is Important at Different Times</td>
<td>Care I Receive Now</td>
<td>&quot;Well, I have a therapist. I also have a psychiatrist who I only see every couple of months for medication. I was in group therapy also, but after I lost my mother in July I started a grief support group instead.&quot;</td>
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<tr>
<td>Choosing What Care is Important at Different Times</td>
<td>Where I Receive Care</td>
<td>&quot;The grief support group is through a community center. The group therapy was in a hospital.&quot;</td>
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<tr>
<td>Differences in Therapists' Approach</td>
<td>My Experiences with Care</td>
<td>&quot;Some therapists keep a dialogue and will kind of talk to you, 'Well, okay, you said that, so I see how that related to that,' but I haven't had all that many who have been that astute or whatever you want to call it.&quot;</td>
</tr>
<tr>
<td>Lack of Connection with Therapist</td>
<td>Lack of Connection with Therapist</td>
<td>&quot;I dunno what's going on with this therapist, unless it's just that I'm more depressed and I'm not finding levity in anything, But some of the things that he's finding funny, I'm just not finding funny. I guess he's maybe just nervously laughing about something.&quot;</td>
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<tr>
<td>Care that Didn't Feel Helpful</td>
<td>Care that Didn't Feel Helpful</td>
<td>&quot;They started to feel at some point that I should get into Dialectical Behavior Therapy. The first experience I had with it didn't feel really helpful to most of us in the group, because they weren't showing us how it could relate to our own life and how we could use it every day. So, I don't think I got so much out of that one.&quot;</td>
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"So, that's when I got involved with my psychiatrist slash psychoanalyst. I think, looking back on it, that working with him triggered my posttraumatic stress, because the psychiatrist was an older man and my grandfather had been an older man. He also had a walk down type of office and he had couch-type thing. He didn't have me on the couch, he had me sitting up. But I just started getting worse and hearing voices and I started hallucinating things and I was in and out of hospitals. So, I wasn't doing well at all. His type of therapy, where you don't even say hello to the person, that was not for me at all. It was just so impersonal. And then he really wouldn't talk that much at all and sometimes I couldn't talk and I would just be looking at the floor and there would be silence for almost 50 minutes and so that was not really conducive to me speaking or feeling comfortable or anything like that."

"I had been with this artist for a year and I was in love with him. He was an older man though and he had gotten into debts and decided he needed to go back to Alaska, 'cus at that time the pipeline was big and he could make big money. And so he decided that's where he was gonna go, but that just really hit me badly and that's when
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<tr>
<th>Not Being Listened To</th>
<th>Not Being Listened to About Medication</th>
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<td>I ended up in the hospital. When I tried to say to the doctor, 'I think there's something here and I'm not dealing well with his leaving' and all that, he just said, 'Well, there's nothing to do with that.'</td>
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| "And at that point he had said I was paranoid schizophrenic and so then he was pushing all these heavy-duty so called tranquilizers and I kept telling him, . . . 'I'm feeling worse and I'm feeling more anxious and more paranoid' and all this and he'd say, 'No, no, no. You can't possibly, because these are supposed to treat that.'" |

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<tr>
<th>The Effects of Medication</th>
<th>Medication Not Working</th>
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<tr>
<td>&quot;Medication has not worked well for me, even now.&quot;</td>
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<th>The Effects of Medication</th>
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<td>&quot;The medication I'm talking about, Lorazepam or Ativan, seems to put me in a less depressed mood and to make me want to live.&quot;</td>
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<th>Lack of Continuity with Care</th>
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<td>&quot;It's too bad they don't have some kind of a graduation group. But I guess they expect that you'll get together with those friends or whatever and do your own things. But it might be a nice thing to have somebody that was a stuff too, in case you wanted to bounce certain things off of them and stuff.&quot;</td>
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<tr>
<th>Not Having Needs Met or Feeling Uncertain if They Will Be</th>
<th>Not Having Needs Met</th>
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<td>&quot;And as far as doing the trauma part of it, I feel like that's still something that needs to be addressed and I don't feel like I'm with a therapist that I would do it worth.&quot;</td>
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| Not Having Needs Met or Feeling Uncertain if They Will Be | Feeling Uncertain of Whether Needs Will Be Met | "And then we go into the interview and I guess the interviewer didn't know that I was going to be there with the staff member. So she kind of looked at me like, 'What're you doing here?' And so that got me even more within myself and I thought, 'Oh, gosh.' So she took the vocational person in and talked with her and then she came out and she was warmer and offered her hand to me and said, 'Well, come on in.'"

| Not Being Treated with Respect or Fairness | Not Being Dealt a Fair Option | "Unfortunately, I haven't had such a good experience as far as trying to go back to work and I feel that I wasn't dealt a fair option in that area."

| Not Being Treated with Respect or Fairness | Not Being Treated with Respect | "And so when we get into the meeting with the vocational support staff, she's like looking all the sudden at me and with this smile and she says, 'Well, now you're an artist, so what's to stop you from whiting this out and writing something different in there?' And the educational support staff said to her, 'Why on earth would you say that to her? That doesn't apply at all.' And she goes, 'She's never done anything that's been underhanded or not decent or honest.'"

| Fearing Their Power and Not Trusting that I'll Be Treated Well | Fearing Their Power | "But I didn't say too much because you feel like they're in the power and they can do what they want if they so desire. I feel like, well I don't want to end up in the
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<th>Fearing Their Power and Not Trusting that I'll Be Treated Well</th>
<th>Not Trusting that I'll Be Treated Well</th>
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<td>&quot;But I'm just thinking that maybe they see that another person knows what's going on. It's kinda like having a witness. Of course, I have trust issues so that's why I kind of get all upset and wonder if this is gonna be taken care of or not and all that.&quot;</td>
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<tr>
<th>Trauma and Stress in My Life</th>
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<td>&quot;I was sexually abused by my grandfather, so I suffer from post traumatic stress in addition to major depression and anxiety. For the past 10 years, maybe less than that, I've been the primary caregiver for my mother, who had dementia and a lot of physical problems. I also, in the course of that, became estranged from my sister and brother. So, that was like an ongoing problem for me and a great stress.&quot;</td>
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<th>Trauma and Cutting</th>
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<td>&quot;I was using a scalpel, but my father found that out and he took that away. But it seemed I couldn't stop doing it and I just hated myself and I would burn myself. Well, at one point I used our electric carving knife on myself. I just really hated myself and at that point in my life I was blaming myself for the whole sexual thing and I thought I must have done something to get my grandfather to do that. Of course, in the trauma group, I learned that wasn't the case.&quot;</td>
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<tr>
<td>Feeling Unable to Seek People Out</td>
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<td>&quot;I have a great fear of people that I feel goes back to my trauma and it wasn't only that trauma, with my grandfather, but I think that was the biggest one. So, I have a fear of people and where others would gravitate to people and want to seek them out and talk to them, I can't always do that, especially if I feel in a really depressed way. I can just isolate myself and not reach out to people.&quot;</td>
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<th>Love Ended Cutting</th>
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<td>&quot;But it wasn't until I started taking care of my nephew before he went to kindergarten that I stopped cutting . . . I just felt really close to him and he felt close to me and it was love I needed.&quot;</td>
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<th>Getting Support</th>
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<td>&quot;Most of my experiences with the Clubhouse were good. For a while, I really felt connected and seemed to be liked by a lot of people at the Clubhouse. And in fact I became like a volunteer leader.&quot;</td>
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<td>&quot;I live in subsidized housing. It's mostly for elderly, but there are a few of us that are younger and disabled or whatever. And the resident advisor is a very kind person and so I feel less alone because I can go to her about different things that come up, financially or just housekeeping type things or whatever.&quot;</td>
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<tr>
<td>The Clubhouse Offers Community</td>
<td>Care that Feels Better</td>
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<td>&quot;I think the Clubhouse was helpful to me and I think clubhouses are helpful . . . Like, we used to do a lot of different things that I probably wouldn't have gotten to do and at that time you only had to pay five dollars and what they did was they kind of put that into a pool of money and so they would pay the rest, like if we went to a movie or something like that. So they made it very affordable and they don't do that now. It's one major outing that they do and they don't to the weekends like we used to do. Because a lot of people, I think, on the weekends can feel like at a loss&quot;</td>
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<th>How Family Impacts Coping</th>
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<td>&quot;One of the first psychiatrists that I was with for about ten years, at one point he said to me and he said it to my parents to, he said, 'I get her feeling better about herself and then she comes home to the family life and she's down again and being taken down,' and he said, 'that's not working to help her.'&quot;</td>
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<th>How My Family Felt</th>
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<td>&quot;My first attempts to find care were kind of hit or miss, because my parents were not behind me getting involved in therapy. They're from a different generation altogether and they didn't want people knowing that I was going to be in care.&quot;</td>
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| How I Got Connected to Care | How I Got Connected to Care | "A professor of mine told me about a woman who people sometimes spoke too when they weren't living up to their intellectual potential or when they were having psychological problems. He wanted me to see her and so I contacted her. At that point, I was working in advertising. She gave me the name of this person to go see, but it was weird and he couldn't see me regularly and was more interested in giving me meds."

| Speaking Up for Needs and Making Decisions About Care | Speaking Up for Needs | "So, after having humiliating experiences with her, I finally did switch with the help of an advocate who came in and we talked with her boss and I just switched to somebody else."

| Speaking Up for Needs and Making Decisions About Care | Making Decisions About Care | "Now my regular psychiatrist is telling me that I really should get off of that medication, that it's been linked with Alzheimer's and that type of thing. But since my mother died I'm really not in a good place at this point. So, I had tried not using it and just using it sparingly and all that. But this past time I saw him I said I would sign something releasing him from any responsibility of anything, I said, but I don't think I can completely do without this or having it available if I did need it or whatever. And so he said, 'Well, you don't have to sign anything, I'll just put it in your chart.'"
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<tr>
<th>Being a Leader</th>
<th>Being a Leader</th>
<th>&quot;I ended up being the leader of the trauma research group, which I didn't intend initially.&quot;</th>
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<td>Speaking Out</td>
<td>Speaking Out</td>
<td>&quot;So finally, in one of our group meetings, I just said 'I'm sorry, but I'm not going to be able to not say this to everyone in this group and, you know, I'm sorry if this upsets this particular person, but I'm upset and I'm triggered and I need someone to help me with this and maybe some of the other people do also.' So, we then had a woman that worked in their emergency services and she actually was a trauma specialist, so she came into some of our groups.&quot;</td>
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<tr>
<td>Not Trusting Self</td>
<td>Not Trusting Self</td>
<td>&quot;I was just so sick and then I felt like, well, if I give up on this then I am just kinda wimping out and maybe I need to hear what he's saying or need to do this&quot;</td>
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<tr>
<td>Feeling Anxious about Capabilities</td>
<td>Feeling Anxious about Capabilities</td>
<td>&quot;Some people have encouraged me about trying to pursue my art and all that, but, I dunno. I've always found it hard, even when people have been artists themselves and they've looked at my work, I've still felt like they can't be telling me the truth. They're saying it's good, but how do I really know. I just kinda doubt myself and all that. But, they've tried to build me up and tell me positive things.&quot;</td>
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<tr>
<td>Not Being Offered a Chance</td>
<td>Not Being Offered a Chance</td>
<td>&quot;And most times, when the people did meet me, they seemed to find something they could say was good&quot;</td>
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about my artwork or this or that. But they all wanted me to know the computer, which I had never gotten into. I said, 'Well, could I do an internship?' And they said, 'Well, no, because we've had people in the past and it hasn't worked out.'"

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<thead>
<tr>
<th>Not Being Offered a Chance</th>
<th>Being Looked Down On</th>
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<tr>
<td>&quot;I found that they were looking down at a person with a mental illness and not giving me a fair try at things.&quot;</td>
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