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Mental Health Disabilities, Shame and the Family: The Good, the Bad, the Chosen, and the Imagined

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Abstract: Based on ethnographic research examining the lives of individuals with mental health disabilities in Suffolk County, New York, this paper highlights key aspects of deinstitutionalization, intersectional shame factors impacting disabilities, and community-based mental health care. Findings indicate that individuals' families of origin can promote and maintain shame and psychological distress.

Keywords: Disability; Shame; Family

This paper highlights the phenomenology of individuals with mental health disabilities in Suffolk County, New York. The project considered involuntary commitment, deinstitutionalization, community-based mental health care, family, and transition processes. Findings indicate people's families of origin can create and sustain aspects of shame and psychological distress. As individuals seek compassion and care they had reported that it was lacking during their institutionalization, and they often instead experience shunning and exclusion outside of hospitals or mental health housing. In effect, while large asylums are considered modalities of the past, *total institutions*[1] (Goffman, 1961) remain and are often recreated by systems of care, families, and society effected by expanding historical shame, discrimination, and violence against people with disabilities.

Purpose for Study

The compounded marginalization of people with disabilities[2]—intersections of racism, sexism, classism, and trauma they endured—motivate this research. Individuals with mental health issues are persistently ignored or invisible (Deutsch, 1949; Fanon, 2004; Neugeboren, 2006). Prior to the late 20th century, most people with persistent mental health needs were institutionalized indefinitely. Later, post-deinstitutionalization, those without financial and emotional support ended up homeless, and were (and still can be) relegated to sub-standard and unsafe housing or in jail (Ben-Moshe, 2011; Jenkins, 2015; Neugeboren, 2006). Others live in contingent—considered as provisional or unchosen—housing sites, often becoming more disabled by systems and people, including, in a majority of cases also by family members, who further subjugate them as they wait for safer housing (Desjarlais, 1994; Frischmuth, 2013; Hatzenbuehler et al., 2013; Jenkins & Carpenter-Song, 2008).

Though modern approaches to provide services in the most barrier-free environments is an improvement over institutions of the past, some theorists argue that community-based mental health continues to disable people socially, economically and politically, or to the same degree as historic asylums once did (Ben-Moshe, 2011; Luhrmann, 2007; Reaume, 2002, 2006; Whitaker, 2010). Contemporary care spaces—those in the deinstitutionalization era—intend to generate freedom, but often engender shame and greater cycles of anguish (Clapton, Williams, & Jones 2018). Therefore, attending to current care practices and shame is essential in the era of post-deinstitutionalization.

Asylum History on Long Island

Four state-run asylums (referred to in this study as the “Big Four”) all operated within a 30-mile radius of one another in Suffolk County during the late 19th and early 20th century. At one point these four institutions collectively housed the largest number of people with mental disabilities in the world (Kalvin, 2015; Polaski, 2003). Medical opinion of late 19th and early 20th centuries professed that removing people with mental disabilities from the stressors of city life promoted flourishing and mitigated disabling effects of mental differences (Kalvin, 2015). These spaces encouraged families to bring individuals with mental health disabilities in for treatment (Gamwell & Tomes, 1995). The grounds were beautiful and the treatments were touted as state of the art. There was far less guilt to manage for the family members, who were discarding loved ones at the asylums (Gamwell & Tomes). Thus, these new environments served two purposes: they isolated the “sick” individuals by removing them from exacerbating effects of the city, while also protecting the city residents from their embarrassing and menacing deeds. Meanwhile, the pastoral settings, touted as functioning without restraints at that time, would restore health. Participants in this study reported that their families’ desired the same for them—to isolate and rehabilitate them in asylums—in settings away from home where they would not bring attention and disgrace upon the family unit nor disrupt the normal flow of activities.

Methodology and Fieldwork Site

Through in-depth interviews and participant observation in community-based, peer-delivered recovery programs, and in publicly supported mental health housing sites in Suffolk County, New York, findings illuminate how individuals with persistent mental health disabilities describe and feel about their own living environments and occupations. During the following analysis, of a small portion of this data, the consented participants in this study are referred to as individuals. Data was collected from qualitative, semi-structured interviews with individuals in Suffolk County. Individuals were engaged with for nearly 23 months spanning from September 2015 until August 2017. In September 2015, interviews were conducted, peer-based mental health conferences and peer support groups for family and individuals with mental health disabilities were attended, and service providers were consulted. Research flyers were also distributed electronically to 230 people on peer listservs. From that pool and through snowball sampling, 38 individuals volunteered for in-person meetings in order to learn more about the research. Of the 38 volunteers, a total of 26 individuals attended these meetings. The meetings included a verbal and written description of the study, an initial verbal capacity to consent[3] screening, and a final written consent if capacity to consent was completed. Individuals who passed the capacity to consent, and were either Suffolk County residents from the Big Four or residents that used local, community-based public mental health services, were invited to participate. An incentive of a $25 gift card was given to each participant who completed the initial interview.

Of these 26 individuals, most initial consenting and interviewing meetings lasted 45 minutes to 1.5 hours. Three people chose to meet in private rooms on the Stony Brook University campus. The remainder of people were interviewed in their homes, which were mental health housing sites or privately-owned homes, or if they felt comfortable, at local libraries, mental health agencies where they attended day programs, or at nearby pizza and coffee shops. On three occasions, one individual's meetings occurred in an acute psychiatric ward, although she was medically stable, she was awaiting a community housing assignment. Nine of 26 individuals (34.6%) completed only one meeting. The remaining 17 individuals (65%) completed two to three meetings, as well as, speaking on the phone or emailing back-and-forth. In the case of seven individuals (26.9%), there were four to five meetings that took place in various home and public settings. This includes some travel to Mental Health Clubhouse[4] activities, other mandatory mental health program sites, having coffee, doing shopping errands or joining them for meals. When individuals agreed, research meetings were conducted with other sites they visited regularly, to get a better feel for their lives and worlds. Additionally, many follow-up interviews took place at community-based mental health housing and day program sites.

The first and second meetings were recorded and transcribed verbatim. Field notes were also conducted during these visits. After the first two meetings, subsequent meetings were recorded but not always transcribed verbatim, only for clarity when necessary. But most of the later meetings, beyond the first and second meetings, where individual's day-to-day occupations were being ascertained, meetings involved more participant-observation in order to understand what daily schedules and routes looked like. Codes or themes found in transcript verbatim and field notes were created and compiled immediately after each interview.

Questions were open-ended but started with requests for individuals' memories of the first time they became aware or were told they may have a mental health disability. They were asked to describe where they grew up and when they first engaged with any form of mental health treatment or lived in a facility dedicated to mental health or psychiatric services. Of note, was the fact that the majority of people interviewed, 25 out of 26, described some form of abuse or trauma in their family of origin, as well as, multiple experiences in and out of mental health housing or hospitalizations. Twenty-three out of 26 also described compounded feelings of stress related to their gender, social class or ethnic background.

It is important to acknowledge and re-emphasize that these ethnographic examples are drawn from a small sample of people in Suffolk County. From the study sample of 26, extremely brief excerpts of seven individuals' interviews are summarized in this paper. Common themes emerged from each of these individuals with regard to shame, family trauma, forced medication and long-term institutionalization or perceived feelings of containment. None of the study participants' family members were interviewed, so findings were concluded solely from individuals' accounts and research publications relevant to themes that emerged.

Intersectional Mechanisms of Shame

The concept of intersectionality underscores compounded biases and structural inequalities relayed by individuals in this study. For instance, Keisha (a pseudonym)[5], a Black, bi-sexual female, who participated in the study, feels intersecting pressure points (such as race, class, sexuality and gender) toward her disability. Because of her socioeconomic class, she lives in a space *not chosen by her*, but instead was *available to her* where she must learn to advocate for herself and be compliant in order to stay safe. If she remains compliant, she said, she may be considered for less-restrictive housing in the future. Another participant, Dao, a 40-year-old Vietnamese man, feels alone as an Asian person with multiple disabilities who is estranged from his adoptive and biological family in predominantly white spaces on Long Island. Lamont, a 45-year-old gay Black man, provides an example of these stakes as well. Because of his race, mental health needs, economic class and sexuality, he does not feel he has many options to find community and friends. He further isolates himself, as he tries to maintain compliance requirements with community-based programs and benefits, so that he can access medications and general healthcare. Similar sentiments are recounted by Daniel, José, Helen and Patrice—all of whom described demeaning experiences with family, medications, and involuntary hospitalizations. These seven individuals highlight only a small portion of the multiple layers of shame people in the larger sample described to me.

Trauma: Informing Services Without Further Coercion

The Adverse Child Events (ACE) study (Felitti et al., 1998) teaches us that more than half of people with mental health needs experienced a traumatic experience before the age of 18.[6] For this reason, the aim to circumvent further traumatic events, such as reducing or eliminating coercive psychiatric care, is gaining acceptance by mental health service providers.[7] Given that a large majority of psychiatric patients have a past with trauma, caregivers and clinicians are calling for the need to create more safety (SAMHSA, 2014). Sweeney et al. (2018) note that when delivering services, instead of asking "What is wrong with you," providers are moving toward asking, "What happened to you?" (p. 319).[8]

With these questions in mind, it is interesting to consider contemporary theories about identity, shame and family, alongside individuals' lives. An evaluation of individuals' families based on the, admittedly normative, constructs of "good" or "bad," and "chosen" and "imagined" is presented. Drawing from Michele Friedner (2015) and Angela Garcia (2010), include narratives that are indicative of the binds these categories create for individuals who long for 'good' and helpful family, yet ultimately return to sites and relationships that can be further shameful or 'bad' which exacerbate or promote disabling conditions. Individuals repeatedly used the term 'good' to describe family members or supporters who assisted them in some way, and were consistently in their lives or provided them a place to stay. They used the term 'bad' when referring to traumatic events or people in their lives who were physically, sexually and emotionally abusive. Many times, contradictory terms were used, however, when individuals described a parent as a good person who did bad things. The terms ‘chosen’ and ‘imagined’ represent an ideal that individuals are striving for in close relationships. Many chose new family members to replace biological or legal family members such as guardians and foster parents. Others imagined new family members such as a future spouse, partner or roommate that would make life more complete and fulfilling.

Family Impacts on Disability Shame

While individuals detailed what factors influenced their mental health experiences, family dynamics repeatedly emerged as a factor contributing to how they entered “the system.”[9] Some mental health experts argue that family involvement aides in recovery (Dixon et al., 2015), while others note that certain family dynamics promote more disabling mental health outcomes (Felitti et al., 1998; Stumbo et al., 2015).[10] Based on individuals’ narratives, it became apparent that experiences with family members can indeed both exacerbate and mitigate disabilities. Using a parallel from anthropologist Angela Garcia (2010), family can be variably productive—helpful and harmful. The same family that negatively impacts psychiatric disabilities might at later points be thought to mitigate it. The family can even be doing both simultaneously. Individuals seeking to reintegrate with family from which they had been estranged thought they were returning (and were even eager to do so) to a family of origin because they were trying to undo or overcome conflicts of the past, only to be further subjugated or shamed.

Sixty-nine percent, 18 out of 26, of these individuals grew up in the vicinity of the Big Four asylums and reported their parents or guardians themselves also struggled with mental health issues:

> As young as I could remember, my mom was in Pilgrim State [psychiatric hospital] for mental illness. My foster mom took me to see her in the hospital a lot when I was a kid and it was really sad. My foster mom was okay, but we fought a lot. Even though she knew I had mental illness too, she would just push my buttons. Then my [biological] mom died in Pilgrim. It was hard to understand. My sister and I were also separated; she went with other foster parents far away so I was alone (Lamont).

People like Lamont, quoted above, described phenomena indicative of Garcia’s (2010) summary about heroin addicts sharing the affliction with family. Garcia concludes “there is a complex politics of kin, love and mourning” (Garcia, 2010, p. 149), meaning individuals living with addictions are often fighting and sharing these same struggles with family to the point that they may even have to watch them die doing it. Lamont reported he spent years being resentful toward his biological mother for having abandoned him, and not understanding her disability until he was older and struggled with his own similar symptoms. As a result, after decades of being ashamed, he accepted their shared disabling experiences as possibly genetic and even found empathy toward her. When she died inside the asylum, Lamont said he felt he lost his mother a second time and experienced further abandonment and disgrace because of their disability.

Twenty-four out of 26 study participants (92%), in fact, noted the delicate balance of negotiating concealed patterns of shame and shaming within their families of origin. Including wanting to find belonging after years of feeling inward shame (from within the family unit), and peripheral shame (from outside the family) which was inflicted on them from society. They worked to overcome abandonment and had tried to cover up physical and emotional abuse to protect the family unit. They found less stigma and judgment in new families they chose.

Daniel, a 56-year-old White male, who spent a number of years in and out of two Big Four asylums and now lives in a single apartment treatment program (ATP), described his family:

> My mom and dad kept their drinking and abuse pretty well hidden from the community. They appeared to the neighbors and everyone else as a ‘good’ Catholic family, but at night when we were home from school there were very scary moments. I just wanted my dad to love me and to fit in, but he could never accept that I wasn’t the jock he wanted me to be, even when he tried to beat that into me.

Though he was physically and emotionally “punished for not fitting the mold” as he described, Daniel still ached for his father’s acceptance. Daniel and others described what Elizabeth Pleck (2004) refers to as *domestic tyranny* or the historic patterns of covering up physical and emotional abuse in order to protect the perception of the family unit. Daniel stated that tyrannical control was exacerbated by his father’s drinking. When Daniel’s mental health needs became apparent and his parents were forced to address them, this compounded notions of shamefulness and indignity for Daniel.

Like Daniel, 11 other individuals (42%) described their family ‘forcing’ them into treatment after enduring abuse and disparagement by that same family. Meanwhile, there is a growing trend in mental health care attempts to reduce coerced treatment and move toward an elimination of restraints and forced medication. In recognition of childhood trauma, Trauma Informed Care (TIC) is considered a more contemporary modality that avoids force as the first go-to intervention (Isobel, 2015; NCTIC, 2013; Watson et al., 2014). Felitti et al. (1998) reported that more than 50 percent of people with mental health issues experienced an adverse childhood experience (ACE) prior to 18. Additional studies (Shonkoff, 2016) suggest ACEs have oppressive physiological effects that can damage a child’s developing brain, and this in turn leads to a higher prevalence for later physical and mental health problems.

Eighty-five percent of individuals in this study—22 out of 26—reported memories of at least one ACE, and of these 22, a total of 20 narrated details about two or more ACEs. There were many times some individuals recounted as many as four to five ACEs. They each (every one of the 26) were hospitalized, involuntarily medicated, and in 10 cases, restrained and administered shock therapy.[11] One hundred percent of this sample of individuals—each of the 26 individuals—also, at one point or another, was told by their psychiatrists when being treated they would be disabled for the rest of their lives and would not work. Each person explained that these respective diagnoses and prognoses promoted feelings of what they described as shame and despair from at least one member of their family of origin. Two of the three individuals described that the family was ashamed at the life sentence their respective disability produced. While all three noted that it was the stigma of psychiatric diagnosis itself that also produced a shamefulness—people said they felt the need to hide their diagnoses and the medications prescribed for them. However, when pressed whether families gave reasons of *why* mental health needs were shameful, individuals did not have responses.

Why Family Matters

Pondering accounts of family and kinship may provide singular answers to these questions, but I also caution that I take care *not* to ascribe family roles as one's primary identity. A particular role in the family *can be* one form of identity—a small portion of identity for some, a larger one for others—but it is not necessarily *the only* form of identity. For example, there are stronger and weaker ties—either within family or without family—, where some family is helpful, others are hurtful (Granovetter, 1973), this has caused many individuals to have chosen, ideal, or imagined families (Weston, 1997). Furthermore, many individuals may not have the social capital or privilege to even consider their own roles and identities (Friedner, 2015), making their search for finding chosen families even more difficult. Erevelles and Minear (2010) underscore how intersections like these between disability and class, or gender, can produce "non-citizens and "(no)bodies" (p. 129), or also known as people with disabilities who do not count or who are oppressed.

Further notable, 10 individuals, whose family deemed them "mentally ill" or 'sick' (not my terms, but many monikers reported that their family members used to designate these labels to them), had reported feeling uneasy with these labels. These individuals returned to live with those same families of origin for extended periods of time after institutionalization or hospital stays for said illness. Yet, most still attributed a certain degree of disability and shame ensuing from these early caregiver/family guardian relations—whether blood or adoptive family of origin. Therefore, people knowingly returned to the same environment they described as hurtful or harmful, and longing for a change in circumstance. Individuals recognized that re-engaging with disparaging family could start the entire shame cycle all over again—individuals' symptoms had reappeared at family home sites after their time of hospitalization where they felt 'relatively stable.' Once the individual felt ashamed or demeaned and became agitated, then the family member(s) labeled this as a symptom of their 'disease,' turning them out once again.

Critical disabilities scholar Clementine Morrigan (2017) offers important propositions about the phenomena I call *shame cycle*, particularly in the case of individuals who have experienced trauma and violence in their past. Morrigan notes that people with psychiatric disabilities are often portrayed as or reduced to 'acting out.' This acting out, however, is actually resistance against previous and future violence or an "embodied form of testimony" (Morrigan, 2017, p. 62). Unfortunately, the most common response to this resistance is a desire, on the part of some family and especially psychiatry, to physically or pharmacologically restrain symptoms. Participants in this study, in fact, each noted that family members wanted to protect themselves from harm and avoid family violence by administering more medications. Findings here point to the fact that family of origin—

whether originally helpful or harmful—often works in conjunction with that reactive approach to symptoms, while further perpetuating the myth that people with mental health needs are dangerous or need to be subdued and tranquilized. Rather, as Morrigan and others state (Isobel, 2015; Watson et al., 2014), this only serves to further distance and shame people with mental health disabilities from the family and society in general.

Dao, a 38-year-old, Vietnamese male, living in a community residence (CR), noted a similar experience. If there is any disagreement, he told me, his mother’s first response is to remind him that he is a disgrace and that he needs more medication. “My mom told me I need more medication when I went to see her. I don’t feel like I want more medication though. It makes me feel slow. I just want my family to care about me.”

Care in the context of families takes on a distinctive meaning if we think about the dual role of caring and abandonment or even abandonment as care. João Biehl’s (2004) ethnographic work on the relinquishment of ‘severely mentally ill’ people in Brazil provides a useful milieu with which to examine this phenomenon. Biehl interviewed people at *Vida* in Brazil, an institutional site of ‘dis-belonging’ and exclusion for impoverished disabled people, which originally served as an infirmary, but eventually became what he described as a waiting room for death. Biehl notes that this site serves as one of the many “zones of abandonment” (Biehl, 2004, p. 476) for those considered ‘unknowable’ or left abandoned, as individuals lacking personhood or not worth knowing, in these zones. Suffolk County residents’ narratives like Dao’s resonated with these zones of abandonment because, like the United States, Brazil’s people have fewer choices for long-term care in a post-deinstitutionalization era. There is less money for funding of community clinics, but ample pharmaceuticals readily obtainable. Therefore, as Biehl’s individuals show, “the family is increasingly the medical agent of the state, providing and at times triaging care, and that medication has become a key instrument for such deliberate action” (Biehl, 2004, p. 475). Similarly, Dao said his mother, sister and brother-in-law, began telling Dao years ago precisely when he needs his meds and how much. Dao said he feels his mom thinks “she can boss me around this way.” Biehl concludes that individuals with mental health disabilities share this phenomenon when their “families learn to act as proxy psychiatrists,” choosing the role of acting doctor or nurse (Biehl, 2004, p. 475). And, because of this, Biehl concludes, “families can dispose of their unwanted and unproductive members, sometimes without sanction, on the basis of individuals’ noncompliance with their treatment regimes” (pp. 475–476). This is not to suggest there can be unlimited and non-negotiated care provided by an inexhaustible family, but that there may be a way to include individuals in making decisions about their care as responsible people and/or in concert with the parties in their families.

Beyond that, once a person is relegated to the institution for non-compliance, the goal of managing symptoms or other myriad non-conformity justifies abandonment of the unwanted, and the state vis-à-vis mental health housing sites, such as the community residence (CR), in essence take up the role of family caregiver/proxy psychiatrist. The CR staff will make certain residents are medication compliant and, in this sense, the state or mental health housing construct becomes the new family carer, for better or for worse. With little to do and few friends and family who visit, an individual has the unchosen replacement of their state-sponsored housing and staff reinforcing old carer or shame-producing roles of the family. As one of the staff in Biehl's (2004) ethnography noted, this leads to a lack of love and that “lack of love leaves these people abandoned” (p. 477). Being ‘medication compliant’ at CRs in particular was reported as the number one checklist item for individuals wanting reconsideration of some other housing arrangement (sometimes called ‘changing levels of care’ in Suffolk County or having the ability to move to less restrictive housing), thereby creating “the domestic role of pharmaceuticals as moral technologies” (Biehl, 2004, p. 485). Participants agreed that their care was certainly predicated on this technology.

Domestic Spheres of Influence

Considering kinship and disability, these narratives also underscore what Das and Addlakha (2001) recognize as notions of impairment and disability through “reconfiguration of the domestic sphere" (p. 512). Examining what it was like for parents to accept or reject children that are not normal, they refer to the ‘tyranny of the norms of the parents’ and consider how children can be shamed as they land outside of domestic citizenship. People’s disability muddies their belonging. They are influenced by a role in family but are also often citizens of hospitals and other state institutions. Other times they may be cast out of the citizenship of family and instead fall within the domain of the state, where decisions, even including the right to life, are left to public institutions (Das & Addlakha, 2001). I find this analytic relevant to the individuals in this study, as individuals described confusion from concurrent feelings of both *oppression from* and *longing for* family and parents that had cast them out of the family sphere.

Good and Bad Family

It is interesting to contemplate ‘good and bad,’ and ‘chosen and imagined’ families and what makes up kinship as it relates to the family of individuals with mental disabilities and how people must negotiate diminished or expanded kinship networks. By ‘family,’ those close associations—biological or legal guardian—are considered from early family of origin. This also includes those people who shared a living environment for individuals in their early years and were their primary caretakers. The term ‘good family’ refers to those people in roles who were reported as loving, safe, consistent role models for individuals. Similarly the notion of ‘bad family’ describes those people situated as caretakers for individuals who were reported as inconsistent in their care and nurturing. Caretakers may have been psychologically harmful to the children in their care, physically or sexually abused them, were misusing drugs and alcohol, or had been incarcerated during their rearing, before participants turned 18 years of age.

The reference ‘chosen family,’ designates the associations participants voluntarily selected to be in their family circle—those that they accept and want to maintain relationships with. In some cases, these are the same ‘bad’ or ‘good’ family members with whom they grew up with. In other cases, chosen family is completely different individuals all together—a chosen aunt, uncle, neighbor, friend or teacher who becomes a selected kin in an individual’s life. Beyond these categorizations, ‘imagined family’ signifies that tie or relationship an individual wishes and hopes for. Imagined family may be forthcoming or may never come. Chosen family and imagined family can be in sync, or may never be.

In addition, by using the analytic of domestic citizenship space of family stigma and shame (Das & Addlakha, 2001), individuals' narratives challenge the concept of 'sustaining care.' And more specifically, their experiences underscore how some care is not concerned with optimal thriving in the world—not spiritual or educational work—but is more focused on minimally sustaining people to the very perfunctory point that they simply exist. This further imposes peripheral shame—that shame that individuals experience outside of family as well as from within it. Often when family is the first point of care, the 'bad' can be just barely sustaining. Finally, it is acknowledged here that these categories (*good, bad, chosen, imagined*) are often blurred. These fluctuating groups and roles within individuals' lives may be considered at greater length in future work.

'Good' Family

When individuals talked about their upbringing, eight participants began by reporting that they had a 'good' childhood, then qualified 'good' with some lesser degree of good or an explanation for the less-than-good and shame-filled moments. Thus, 'good' was described as what they want these relationships to be or have been.

Dao, 40-year-old, Vietnamese male, lives in a fully staffed CR or community residence, renamed here, Grace Harbor. He has lived in institutions and in CRs since age 18. He described himself as "mental" and "sick," yet "medication compliant." He said his family was "a good family, but forced me out of the house" because of the former two labels. He said they would tell him he could not stay in the family home because he was "mental" and "sick." He said he now must take his medication and attends a program in the community three days per week as a requirement of his state supported housing. "I don't know why my family won't see me anymore. They tell me I am mental in the head; they tell me I need to be a man and live on my own."

Dao said he enjoyed growing up with his twin brother, mother and father on Long Island. Though he has recollections of his parents fighting considerably, he feels he had a "good family life," yet he adds he was "thrown out" on the streets because of his mental disability and is now not welcome back. Dao said he felt this is 'bad' family behavior, yet he still wants to return to this family. "If I could just go back, I know it would be good."

At another Grace Harbor[12] CR, Keisha lives with nine other people in a two-story Victorian home. Keisha, 31-year-old, describes herself as Black/Puerto Rican. Her residence is run by the same agency as Dao's, and the same name as Dao's CR is used, but is in a different town. CRs such as these in Suffolk County are often about the same size—they usually have eight to 13 residents living in one site—and have full-time staff 24 hours daily.

Keisha recounted what she states was a 'good' relationship with her biological mother, growing up in Harlem, NY. Her mother had nine children to raise, Keisha explained, so she and her twin sister were raised by two different sets of foster parents on Long Island. She said she wished it could have been different, but Keisha still describes her mother as a ‘good’ mother, and as someone who had to do ‘the right thing’ by sending her to live elsewhere. She said both of her foster mothers are ‘good people, too’ but they had ‘bad people’ living with them. Because of this, she spoke out against abuse and rape the ‘bad people’ perpetrated on her and was taken to several doctors. When she was diagnosed with a learning disability and schizophrenia, Keisha was mandated to take medication. Because they considered her ‘acting out’ and ‘misbehaving,’ she was committed to a smaller community psychiatric hospital. She said she often waits for her mother, foster mother, and sisters to come visit her in her CR but they do not. Thus, while Keisha and Dao long for more time with their family, it appeared they were in the zone of abandonment that Biehl (2004) designates. Their families, long ago, passed over the caring and family work to the State.

As Das and Addlakha (2001) note occurs with subjugated family members with disabilities, both Keisha and Dao’s voices were dismissed due to their inability to conform. “It seems that the tyranny of the norms of appearance threw these children out of domestic citizenship into the domain of the state as the only sphere in which their rights, including the right to life could be claimed” (Das & Addlakha, 2001, p. 513). Both Keisha and Dao were rejected as children who could not be normal, they were shameful to the family and hence expelled from the domestic sphere. Additionally, in Morrigan’s (2017) terms, the resistance Dao and Keisha embodied precipitated a reactive approach to symptoms. The families’ reactive approach to Dao and Keisha’s resistance was to further subdue their ‘symptoms,’ thus landing them in hospitals, then CRs.

José, a 54-year-old Hispanic male, described his parents’ attempt to reconfigure the domestic sphere (Das & Addlakha, 2001) by committing him to two separate asylums. He now lives in a family home only about five miles away from Kings Park, one of the asylums where he lived for a number of years. While José’s later trajectory involved being welcomed back to the family, his painful memories of being rejected, shamed, and ‘not normal’ remain with him:

> My dad punished me for not fitting the mold. He would come down the hall after me with a knife. He would tell me I was a loser. The fighting and bickering that was around because of my father’s drinking was finally gone for good once he died. I was glad. I could never understand why my mom put up with it. I hated her for that.

José’s overcoming of his hatred of his mother is notably productive, as Garcia (2010) argues, in the sense that it has created new opportunities for him. He can now spend time with his mother and sister. Prior to that, José said he had trouble respecting his mother because she never left her abusive husband, who continually shamed José. His mother provided just enough care and safety to keep him alive, he said. Yet, she also remained in the same home with this husband who verbally and physically abused her own children, causing what José remembers as a lot of fear and “probably amplified my mental psychosis.” This same father repeatedly chased José with a knife and beat him. Once again, there is a commonality in these trajectories in that ‘good’ family was reported, most people using that exact term, but then described—albeit variably—as somewhat ambivalent and even shame-filled.

‘Bad’ Family

Similar to the ‘good’ descriptions that bared both commonality and variability, ‘bad’ family theme presented itself and was re-stated consistently through these interviews. Now in her 60s, Helen has lived in and out of state-run asylums, she transitioned to state supported community residences and boarding homes from her teens until the last few recent years of her life. She also lived in what was called a ‘family care’ environment post-release from Central Islip, where she had what she described as her “worst living environment ever.” She reported that her food was withheld by the homeowner and there were often numerous insect and rodent infestations. She now rents a room in a large, private house in a community a few short miles from one of the state asylums she inhabited. She shares this room with a friend she met at a prior state-supported CR. She is also living with two other women with mental health disabilities, who live down the hall on the second floor in their own respective rented bedrooms. Helen ceased attending formal mental health day programs regularly years ago, but now sees a psychiatrist for medications and a separate therapist for talk therapy.

Early in life, Helen reported, she also remembered feeling that her family ignored her and pushed her away because of her mental health disability. “I can remember wanting to commit suicide as early as 6-years-old. They just didn’t understand me. So I looked for other family in other places.”

Helen did not fit the ‘normal’ configuration of her domestic sphere (Das & Addlakha, 2001) and was at the mercy of the tyranny of the norms prescribed by the family. Per Morrigan (2017), Helen’s family had an ashamed and reactive approach to her symptoms from a very early point in her childhood. Though she attempted to report incest and abuse, she was told to keep quiet. As such, they responded to her resistance by subduing or ignoring those symptoms and committing her to hospitals. When discussing those memories of sexual emotional abuse and involuntary commitment, she referred to the family as ‘bad.’

Helen’s inability to place her physical and emotional pain also resulted in a longing for some solace. She said she wanted to become accepted in some form of family. Helen’s need for kinship is reminiscent of the integration and inclusion anthropologist Kath Weston (1997), which argues for the creation of bonds among gay and lesbian individuals when choosing their own family outside of bloodline. When individuals are shunned after coming out about their sexuality, they choose other relationships. “By opening the door to the creation of families different in kind and composition, choice assigned kinship to the realm of free will and inclination” (Weston, 1997, p. 110). For many individuals, acknowledging the presence of a mental health disability—even if it was a label handed down by the family itself—created a shunning or shaming similar to what Weston (1997) described in her study of people coming out of the closet. In which Weston’s findings on the reporting of sexuality that did not jive with standard norms for the family, appears similar to the reporting or labeling of having a mental health disability. For example, Helen and Patrice reported that their families told them they were “sick,” but also told them their illnesses were unacceptable. “You just need to be treated,” Helen’s parents told her. In other instances where individuals were forced into treatment—Daniel, Dao, Helen, José, Keisha, Lamont, and Patrice were each involuntarily institutionalized—they reported shame followed by a feeling of loss of membership in their family. At the same time, however, by doing so, individuals were later able to open doors to their own new families as well. This ability to choose their own family confers a free will and choice that they never knew existed. The choice for assigned kinship allows people some agency and autonomy, at least with regard to these newly created relationships and bonds.

Helen and her roommates reported having freely chosen their lives together and making plans for the future together. Down the line, Helen said she imagines her next home, living with her roommate, Diane, in a space they create as their very own, with their own family. Helen said she went a long time growing up, not knowing that she could choose new family, or what Weston (1997) calls *replacements for* or “substitutes for blood ties lost through outright rejection or the distance introduced into relationships by remaining in the closet” (p. 116).

Dao’s perceived exclusion or contingent allowance to remain in a family, as he was cast off as ‘ill’ and incapable of maintaining a normal role within the domestic circle of the family, helped perpetuate the domestic description Das and Addlakha (2001) describe as ‘defective.’Thus, he was denied citizenship within his normal family role in the home, as other adult children are still invited back to stay for long periods of time or spend the night on holidays, Dao is not.

Likewise, Patrice’s compounded experiences of family trauma—physical beatings, significant parental alcohol abuse, along with her own rape outside of the home—were difficult to overcome. She was encouraged by hospital staff to work on talk therapy treatments in addition to medication. When she sought this with her family, to bring them into her healing work, she said they were defensive, ashamed, and called her ‘crazy.’ When she pressed further, her parents encouraged psychiatrists to keep her in hospitals longer and increase her medication. She felt their rejection of her need to work through family trauma, was undermining her ability to move forward. Her attempts were seen as further refusing to comply as Morrigan describes:

> No one wanted to believe that trauma was the cause of my conditions. Even though my mom and dad knew I’d been raped, even though they knew they drank excessively and they hit me, they said *I* needed to be hospitalized. It was *my* fault (Morrigan, 2017, p. 87).

In this regard, for Patrice and many other individuals, as Morrigan (2017) characterizes, after being coerced into care, treatment becomes more about shamed compliance rather than wellness for people. Morrigan (2017), a former psychiatric service user himself, describes this as an extension beyond psychiatric care. This was a shared sentiment. Each individual noted that their family accepted their symptoms as resistance that needed to be subdued and overcome, by consigning their bodies to other sites of care, which always involved ‘medication and treatment’ of those shameful symptoms.

‘Chosen’ Family

The predominant theme of ‘chosen’ or ‘my own, new’ family emerged during interviews often. People conveyed how their trajectories ultimately led to other social relationships that served as replacements for ‘not really good’ or ‘less than good’ family who abandoned them socially and physically. In Helen’s case, selected replacement family consists of two very good friends who are roommates in their privately rented house.

Helen’s concepts represent the ‘pursuit of normal’ that Stephanie Lloyd and Nicholas Moreu (2011) underscore as a constant goal for people. Individuals aim for social inclusion as normal people rather than “irregular, disordered” people (Lloyd & Moreu, 2011, p. 593). Even when housing in a community-based site is secure, people do not necessarily feel that social connections automatically fall into place. In this study’s findings, individuals attempt to create new forms of kinship and rekindle old ones, working to overcome earlier experiences of shame.

‘Imagined’ Family

Although individuals described their created or chosen kinships to me, they still had imagined and ideal relationships in mind where the shame of their permanent disabilities was not an issue. For instance, Helen said she imagines a future in which she and only one roommate have their own place and can enjoy nieces and nephews visiting them often. She imagines having parents and siblings that would have accepted her disability and mental health needs more openly.

Dao imagines a time when his twin brother from Florida lived closer, and a time when he could visit his mother and sister whenever he wishes. He imagines what it would be like to have family that would not ignore him. He imagines being married and having children. At times, the visions of imagined family that individuals described to me appeared to help people as they described feelings of ‘hope.’ Other times, individuals chose to end the topic of imagined family, suggesting it could be uncomfortable or an ideal out of reach.

Conclusion

Research supports that individuals with families who are healthy and supportive tend to have better outcomes (Dixon, et al., 2015; Felitti et al., 1998; Shonkoff, 2016). Those individuals who do *not* have helpful or ‘good family’ must work hard to overcome shame. Those who are considered persistently disabled, who do not exhibit socially-imposed, positive outcomes, like return-to-work or school, or imagine and create these new kinships or ‘replacements for.’ As Kath Weston (1997) notes, this task is both exciting and difficult when there is an absence of good family models in people’s early lives.

As Biehl (2004) emphasizes, when people are left in these zones of abandonment, essentially as unwanted and shameful, “they are sure to become unknowables” (p. 477). On the other hand, as individuals move about in the world—with mental disabilities or not—they come to inhabit public spaces that are modeled after family spaces, or spaces they try to find their bearings in by learning to understand what their public role is. Thus, I deliberately consider the public sense of belonging and worth that my individuals work to have. Some of these are mixed as individuals live in group homes, which provide a chosen family inside their home living space, but are also overlapping a public sphere in the rules, chores, and administrative guidelines that are imposed upon them living there. They endure these recreated domestic sphere spaces while waiting in liminality for an accepting home and family of their choosing and imagination.

Similar to what Weston (1997) argues in her ethnography of lesbians and gays, having a mental disability often constitutes being ashamed or shunned as ‘other,’ which requires renegotiation of family and kinship ties. Weston notes that, “fluid boundaries and varied membership meant no neatly replicable units, no defined cycles of expansion and contraction, no patterns of dispersal” (Weston, 1997, p. 109). This otherness may be likened to that of persons with mental disabilities Das and Addlakha (2001) describe and what Biehl (2004) refers to as negative citizens. Biehl states, “The new role of these abandoned men and women as negative citizens stems precisely from their alleged incapacity to produce anything but bodily infections, parasites, and silent suffering” (p. 485). As Weston optimistically states, however, “the very notion of idiosyncratic choice—originally conceived in opposition to biogenetic givens—lent structural coherence to what people presented as unique renditions of family” (Weston, 1997, p. 109). However, I conclude that people do not end up with glorified chosen families, as chosen families is not an easy category and needs further analysis.

Finally, many of these vignettes have shown, even when family of origin is traumatic, shaming and/or disabling, it is not so easy to leave and stay gone. Sometimes the family is the only form of care available to individuals. However, it can be a dangerous site for care, in which someone returns to the very venue that caused trauma and shame in the first place. Thus, the ambivalent or toxic family can produce another intersection for bias and discrimination.

Given contemporary knowledge about early childhood trauma impacting mental health, this paper aims to show that negotiating family of origins can produce more disabling and shameful experiences. Family ties can continue to complicate and disturb the management of mental health disabilities perpetuating labels of *other, deviant, sick* or *ill* that contemporary disability scholars seek to negate. Alternative kinships can serve to overcome rejection or unworthiness within families of origin, even if simply for a short duration. When possible, people do choose and imagine alternatives to unhealthy, shaming relationships, and creating new family. Compounding effects of unaffordable housing and limited employment on Long Island, New York do not make this straightforward.

Considering people’s individual and collective stories remains crucial to the culture of change in communities. People with disabilities must be recognized as valid knowledge producers in order for worthiness and positive futures to be possible. Intersecting experiences of oppression from classism, sexism, racism and ableism must be communicated and addressed: indeed, attending to questions of intersectionality must be foregrounded as it is possible that this study has overly focused on mental health and diagnostic categories.

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References

Back, L. T., Keys, C. B., McMahon, S. D., & O'Neill, K. O. (2016). How we label students with disabilities: A framework of language use in an urban school district in the United States. *Disability Studies Quarterly*, *36*(4). Retrieved from http://dsq-sds.org/article/view/4387/4481

Baladerian, N. J. (2009). Domestic violence and individuals with disabilities: Reflections on research and practice. *Journal of Aggression, Maltreatment and Trauma*. *18*, 153–161.

Ben-Moshe, L. (2011). Disabling incarceration: Connecting disability to divergent confinement in the USA. *Critical Sociology*, *39*(3), 385–403. doi: 10.1177/0896920511430864.

Biehl, J. (2004). Life of the mind: The interface of psychopharmaceuticals, domestic economies, and social abandonment. *American Ethnologist, 31*(4), 475–496.

Bloom, S. L. (2013). *Creating Sanctuary: Toward the evolution of sane societies*, Second Edition. New York: Routledge.

Bloom, S. L. (2016). Advancing a national cradle-to-grave public health agenda. *Journal of Trauma & Dissociation*, *17*(4), 383–396.

Bloom, S. L., & Farragher, B. (2010). *Destroying sanctuary: The crisis in human service delivery*. New York: Oxford University Press.

Carey, A. C., Block, P., & Scoth, R. K. (2019). Sometimes allies: Parent-led disability organizations and social movements. *Disability Studies Quarterly, 39*(1). doi: http://dx.doi.org/10.18061/dsq.v39i1.6281

Clapton, N. E., Williams, J., & Jones, R. S. P. (2018). The role of shame in the development and maintenance of psychological distress in adults with intellectual disabilities: A narrative review and synthesis. *Journal of Applied Research in Intellectual Disabilities, 31*(3), 343–359

Crenshaw, K. W. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, *43*(6), 1241–1299.

Crenshaw, K. W. (2016). *On intersectionality: Essential writings*. New York: New Press.

Das, V., & Addlakha, R. (2001). Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture*, *13*(3), 511–531.

Desjarlais, R. (1994). Struggling along: The possibilities for experience among the homeless mentally ill. *American Anthropologist*, *96*(4), 886–901.

Deutsch, A. (1949). *The mentally ill in America: A history of their care and treatment from colonial times*. New York: Columbia University Press.

Dixon, L., Kurek, J., Susin, J., Laitman, A., Guzman, K., & Tabakman, L. (2015, October 8). The family and recovery—what works and what doesn't. In-person panel presentation for *Mental Health Awareness Day* at Pilgrim State Hospital.

Erevelles, N., & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literacy & Cultural Disability Studies*, *4*(2), 127–145.

Fanon, F. (2004). *The Wretched of the Earth.* New York: Grove Press.

Felitti, V. J., Anda, R. F., Nordenberg, D., Williamson, D. F., Spitz, A. M., Edwards, V., . . . Marks, J. S. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine.* 14: 245–258. http://dx.doi.org/10.1016/ S0749-3797(98)00017-8

Friedner, M. (2015). *Valuing deaf worlds in urban India.* New Brunswick: New Jersey. Rutgers University Press.

Frischmuth, S. G. (2013). Keep your sunny side: A street-level look at homelessness. *Culture, Medicine, and Psychiatry*, *38*, 312–323.

Gamwell, L., & Tomes, N. (1995). *Madness in America: Cultural and medical perceptions of mental illness before 1914*. Ithaca: Cornell University Press.

Garcia, A. (2010). *The pastoral clinic: Addiction and dispossession along the Rio Grande*. Berkeley, CA: University of California Press.

Goffman, E. (1961). *Asylums; Essays on the social situation of mental patients and other inmates.* Garden City, NY: Anchor Books.

Granovetter, M. S. (1973). The strength of weak ties. *American Journal of Sociology*. *78*(6), 1360–1380.

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health, 103*(5), 813–821. doi:10.2105/AJPH.2012.301069

Isobel, S. (2015). Because that's the way it's always been done: Reviewing the nurse-initiated rules in a mental health unit as a step toward trauma-informed care. *Issues in Mental Health Nursing, 36*(4), 272–278.

Jenkins, J. H. (2015). *Extraordinary conditions: Culture and experience in mental illness*. Oakland, CA: University of California Press.

Jenkins, J. H., & Carpenter-Song, E. A. (2008). Stigma despite recovery: Strategies for living in the aftermath of psychosis. *Medical Anthropology Quarterly*, *22*(4), 381–409.

Kalvin, S. (2015, June 3). Volunteer museum tour operator and employee of Pilgrim Psychiatric Center. In-person interview and tour proceedings at Long Island Psychiatric Museum, Brentwood, NY.

Kessler, R. C. (2000). Posttraumatic stress disorder: The burden to the individual and society. *Journal of Clinical Psychiatry*. *61*, 4–12.

Liebowitz, C. (2015). I am disabled: On identity-first versus people-first language. Retrieved on July 23, 2019, from https://thebodyisnotanapology.com/magazine/i-am-disabled-on-identity-first-versus-people-first-language/

Lloyd, S., & Moreu, N. (2011). Pursuit of a ‘normal life’: Mood, anxiety, and their disordering. *Medical Anthropology*, *30*(6), 591–609.

Luhrmann, T. M. (2007). Social defeat and the culture of chronicity: Or, why schizophrenia does so well over there and so badly here. *Culture, Medicine and Psychiatry*, *31*, 135–172.

Morrigan, C. (2017). Failure to comply: Madness and/as testimony. *Canadian Journal of Disability Studies*, *6*(3), 61–91.

Mauritz, M. W., Goossens, P. J., Draijer, N., & van Achterberg, T. (2013). Prevalence of interpersonal trauma exposure and trauma-related disorders in severe mental illness. *European Journal of Psychotraumatology*, *4*, 10.3402/ejpt.v4i0.19985.

Mock, S. E., & Arai, S. M. (2011). Childhood trauma and chronic illness in adulthood: mental health and socioeconomic status as explanatory factors and buffers. *Frontiers in psychology*, *1*, 246. doi:10.3389/fpsyg.2010.00246

Mueser, K., Rosenberg, S., Goodman, L. A., & Trumbetta, S. L. (2002). Trauma, PTSD and the course of severe mental illness: And interactive model. *Schizophrenia Research*, *253*,123–143. doi:10.1016/S0920-9964(01)00173-6.

Mueser, K., Trumbetta, S. L., & Rosenberg, S. (1998). Trauma and posttraumatic stress disorder in severe mental illness. *Journal of Consulting and Clinical Psychology*. *66*, 493–499.

National Alliance on Mental Illness. (2019). Mental health facts in America fact sheet. Retrieved August, 5, 2019 from https://www.nami.org/NAMI/media/NAMI-Media/Infographics/GeneralMHFacts.pdf.

National Center for Trauma Informed Care (NCTIC). (2013). Creating a place of healing and forgiveness: The trauma-informed care initiative at the women’s community correctional center of Hawaii. *National Association of State Mental Health Program Directors, Advocates for Human Potential, Inc., Substance Abuse and Mental Health Services Administration.* Retrieved September 24, 2017, from https://www.nasmhpd.org/sites/default/files/7014_hawaiian_trauma_brief_2013(1).pdf

National Institutes of Mental Health (NIMH). (2016). Prevalence of serious mental illness among U.S. adults by age, sex, and race. Retrieved December, 27, 2018, from https://www.nimh.nih.gov/health/statistics/mental-illness.shtml#part_154787.

Neugeboren, J. (2006). *Transforming madness: My brother, madness, and survival.* New Brunswick, NJ: Rutgers University Press.

Pleck, E. (2004). *Domestic tyranny: The making of American social policy against family violence from colonial times to the present.* Chicago: University of Chicago Press.

Polaski, L. (2003). *The farm colonies: Caring for New York City's mentally ill in Long Island's state hospitals.* Amityville, NY: Official Offset Printing Corporation.

Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients' activism in North America. *International Journal of Law and Psychiatry*, *25*, 405–426.

Reaume, G. (2006). Mad people's history. *Radical History Review*, *94*, 170–182.

Seng, J. S., Lopez, W. D., Sperlich, M., Hamama, L., & Meldrum, C. D. R. (2012). Marginalized identities, discrimination burden, and mental health: Empirical exploration of an interpersonal-level approach to modeling intersectionality. *Social Science & Medicine*, *75*(12), 2437–2445.

Sequenzia, A. (2016). Person first language and ableism. Retrieved July 23, 2019, from Ollibean: https://ollibean.com/person-first-language-and-ableism/

Shonkoff, J. P. (2016). Capitalizing on advances in science to reduce the health consequences of early childhood adversity. *Journal of American Medical Association Pediatrics*, *170*(10), 1003–1007.

Stumbo, S. P., Yarborough, B. J. H., Paulson, R. I., & Green, C. A. (2015). The impact of adverse child and adult experiences on recovery from serious mental illness. *Psychiatric Rehabilitation Journal*, *38*(4), 320–327.

Substance Abuse Mental Health Services Administration (SAMHSA). (2014). SAMHSA's concept of trauma and guidance for a trauma-informed approach. Retrieved on February 7, 2016, from https://store.samhsa.gov/system/files/sma14-4884.pdf

Sweeney, A., Filson, B., Kennedy, A., Collinson, L., & Gillard, S. (2018). A paradigm shift: relationships in trauma-informed mental health services. *BJPsych advances*, *24*(5), 319–333. doi:10.1192/bja.2018.29

Titchkosky, T. (2001). Disability: A rose by any other name? "People-first" language in Canadian society. *Canadian Review of Sociology and Anthropology*, *38*(2),125–140.

Watson, S., Thorburn, K., Everett, M., Fisher, K. R. (2014). Care without coercion—mental health rights, personal recovery and trauma-informed care. *Australian Journal of Social Issues*, *49*(4), 529-–549.

Weston, K. (1997). *Families we choose: Lesbians, gays, kinship.* New York: Columbia University Press.

Whitaker, R. (2010). *Anatomy of an epidemic: Magic bullets, psychiatric drugs, and the astonishing rise of mental illness in America*. New York: Crown Publishers.

Endnotes

1. Goffman (1961) defines a *total institution* as, "a place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed, formally administered round of life" (p. 11).
2. In an effort to support and maintain what Back et al. (2016) notes as a "more positive disability identity," this paper and its author employ people-first language. However, it is important to recognize that disability first language is also proposed as positive by some scholars and activists (see, for example, Liebowitz, 2015; Sequenzia, 2016; Titchkosky, 2001).
3. Any individual considered to be of impaired decision-making capacity in section 6.9 of the Stony Brook University (SBU) Human Subjects Standard Procedures Manual were to be excluded. This would have included anyone who was unable to provide consent prior to the initial interview. A measure to assess 'capacity to consent' was administered to each individual. Any individual who did not answer 10 out of 10 questions correctly on the capacity to consent assessment were to be thanked for their time, but not be included as a participant to enter the study. However, each of the 26 individuals who attended the first meetings passed capacity to consent.
4. Mental Health Clubhouse (MHC) is a pseudonym for a local day program started by former survivors of local asylums in Suffolk County, NY. There are several 'clubhouse' type facilities in the area. One clubhouse's administrators agreed to vet me as a researcher/volunteer for which I underwent fingerprinting and volunteer training. As a volunteer at the MHC, I was invited to attend peer group counseling and therapy sessions as well as make announcements about the research project at peer mental health worker trainings. I sought meetings and similar authorization from three other mental health housing agencies which did not grant me access. I also made announcements at Suffolk County sponsored mental health conferences. Many referrals came from other participants who initially agreed to be in the study, ultimately leading to 12 participants cultivated through snowball sampling.
5. Each person that consented to the study was assigned a pseudonym per Stony Brook University IRB requirements and due to the researcher's concern for anonymity, though more than half of individuals were willing to divulge their identity. Keisha is one of 15 out of 26 consented individuals who were willing to use her legal name. However, pseudonyms were assigned to all individuals.
6. It is unclear how many people without mental health needs also experienced trauma. It is estimated that as much as 51 to 98 percent of trauma goes undetected and untreated (Kessler, 2000; Mauritz et al., 2013; Mueser et al., 2002, 1998) as does a 51 to 80 percent of mental health needs, depending on age, sex and ethnicity (NIMH, 2016).
7. Solid associations between physical violence or trauma, race, class, gender and disability are well supported (see for example, Crenshaw, 1991, 2016; Lewis, 2017; Seng et al., 2012.).
8. See also Bloom 2013, 2016; Bloom & Farragher, 2010; Mock & Arai, 2011; SAMHSA, 2014, for more work on trauma and mental health.
9. *The system* is a term many participants used to describe their use of mental health services or a feeling of entry into and containment within—everything from having been previously institutionalized in of the Big Four asylums, going to jail or shelters, as well as accessing community programs, or now living in mental health housing and accessing local counseling and/or psychiatry.
10. Previous studies about family mitigating and impacting people with various disabilities reflect a similar mix of helpful allies or harmful abusers (see for instance, Baladerian, 2009; Carey et al., 2019.
11. The National Alliance on Mental Illness (2019) estimates that 20 percent of Americans, experiences a mental illness in [any] given year. Given that the estimated population of Suffolk County was 1.49 million as of 2010, per United States Government Statistics, this would equate to about 298,000 people in the County with mental health needs.
12. All CRs, participants and town names have been changed to retain confidentiality.