

Research Article

Crippling Care for Individuals with Psychiatric Disability: Looking Beyond Self-Determination Frameworks to Address Treatment and Recovery

Meghann Elizabeth O'Leary
University of Illinois Chicago

Abstract: This paper seeks to intervene in mental health discourses of self-determination as well as disability studies discourses concerning care. Attending to the material, gendered, and racialized individual care needs of living, cooking, cleaning, working, and raising children is an affirmative step towards alleviating the difficulties in navigating mental distress and treatment for white women and, especially, women of color in the global north.

Keywords: care, self-determination, psychiatric disability, disability studies

Care as it is currently framed in the global north is a widely contested term, with varying connotations including burden, dependency and need, as well as reciprocity, emotional fulfillment, and necessity (as part of the life course). Everyone, at some point in their lives, will require care. Disability studies scholarship around care investigates and critiques these central issues including dependency, disabled persons as care burden, and exploitation and abuse. One line of this scholarship offers new conceptualizations of care such as interdependence, and reframes dependency to include the moral, ethical and affective aspects of caregiving and receiving (Kelly, 2013, 2016; Kittay, 2011; Shakespeare, 2000). Disability studies scholars have also addressed the oppressive material conditions of transnational capitalism that impact caring relationships (Erevelles, 2011c). While physical disabilities as well as more profound and cognitive disabilities are entering the conversation within disability studies, the unique issues surrounding care for people with psychiatric disabilities are just recently emerging. This paper seeks to intervene and move the conversation forward about care and psychiatric disability in disability studies theories of caring and mental health theories of self-determination. The paper especially complicates that idea that fostering self-determination is the primary path to recovery from psychiatric disability.

Feminist disability studies scholar Margaret Price (2015) contends that care for crip “body/minds” “must emerge between subjects considered to be equally valuable (which does not necessarily mean that both are operating from similar places of rationality), and it must be participatory in nature, that is, developed through the desires and needs of all participants” (p. 279). I seek to build on this notion, suggesting that basic care needs are often neglected in mental health and disability studies literature concerning care. Mental health professionals advocate for self-determination, person-centered planning and peer support as crucial elements in treatment and recovery for persons with psychiatric disability (Corrigan et al.,

2012; Davidson, 2016; Mancini, 2008). While peer support is less individualized and more community oriented, the majority of these treatment options ignore the material and structural conditions of racism, sexism and poverty that contribute to a person's mental distress, placing the onus of recovery on the individual with a psychiatric disability. This paper offers a feminist materialist framework that attends to the caring needs of people with psychiatric disabilities while highlighting the fact that these needs are often gendered and racialized.

My own concept of feminist materialism in disability studies draws on the work of Price and feminist disability studies scholar Nirmala Erelles, who have both moved the conversation surrounding care and mental disability forward in highly generative ways. Erelles situates the construction of disability within the broader material frameworks of transnational capitalism and exploitation. This includes "historical and economic conditions that situate becoming disabled in a violent context of social and economic exploitation that may inhibit as well as complicate oppositional/transgressive theorizations of disabled subjectivity" (Erelles, 2011a, p. 38). Erelles, in particular, challenges post-structuralist and humanist disability studies scholars for not adequately addressing the material oppressions created by transnational capitalism, such as racism, sexism and classism. Erelles argues that the humanist transgressive possibilities of disabled subjectivity theorized by disability studies scholars Tanya Titchkosky and Margaret Shildrick, unintentionally foregrounds "the bourgeois non-racialized disabled subject with the 'material' freedom to offer a more transgressive reading of disabled subjectivity" (Erelles, 2011a, p. 38). Price builds on the materialist work of Erelles to explore her conception of "bodymind," which she defines as "a socio-politically constituted and material entity that emerges through both structural (power- and violence-laden) contexts and also individual (specific) experience" (Price, 2015, p. 271). The conflux of sociopolitical constructions and material entities that define "bodymind," for example, as emerging from "structural" contexts, such as transnational capitalism, as well as individual experience are crucial to my own understandings of care in relation to psychiatric disability.

I begin with a review of current disability studies literature surrounding care, as well as current mental health literature on self-determination. Utilizing an autoethnographic approach, I explore my own complex relationship to care and self-determination, revealing the often-unacknowledged material conditions that contribute to mental distress. My varying use of the terms psychiatric disability and mental distress is not intended to conflate the two identifying terms, or to establish unintended hierarchies in regards to psychiatric disability. My use of the two terms is meant to acknowledge the differing ways people I have spoken to define and articulate their experiences with what is commonly diagnosed as depression, psychosis, anxiety, mania, etc. From my own perspective, identifying as having a psychiatric disability includes the experience of mental distress. However the experience of mental distress does not necessarily result in identifying as a person with a psychiatric disability. I draw on a feminist materialist framework (Erelles, 2011c) to demonstrate the ways in which current theories of care and self-determination neglect the needs of many people

struggling with mental distress who also navigate the intersectional oppressions of sexism, racism and poverty. I argue for a politics of care that attends to these needs. In particular, I attend to Erevelles' feminist materialist framework that places theories of disability in the broader context of transnational capitalism.

Dependency, Interdependency and Care

Disability studies scholars who take up issues of care theorize about how best to address the care needs of individuals with disabilities in a number of different ways. One line of scholarship demonstrates how social policy has failed to adequately address problems of exploitation and abuse that affect both caregivers and care-receivers. Other scholars, drawing on theories of humanism and post-structuralism, argue for a complete dissolution of the divide between carer and care-recipient, while still others assert that a dissolution of these roles is not possible, or even desirable given the current context of exploitation of care-workers and the oppression of persons with disabilities within transnational capitalism (Erevelles, 2011b; Kelly, 2016; Kittay, 2011; Shakespeare, 2000; Watson et al., 2004).

Tom Shakespeare (2000) is a disability studies scholar who is particularly influential in moving conversations surrounding disability studies theory and disability policy forward in productive ways. In regards to care for disabled people his work expands and complicates the arguments of the independent living model (IL), which asserts that the relationship between disabled people and their personal care attendants (PCA) is a strictly economic interaction between the employer, the person with a disability, and the employee, the PCA. Shakespeare suggests that the IL model is a major advance in providing adequate services to disabled people, but care for disabled people still needs to be reformed. This reform can happen by balancing the IL model, based on an ethic of rights (and rules), with a feminist ethic of care, based on relationships and responsibilities (p. 60). A feminist ethic of care provides a framework to challenge prevailing Western notions of autonomy and independence. It focuses on the moral components of human connectedness and the maintenance of relationships through which our obligations to others are both acknowledged and put into practice. The ethic of rights is considered more masculine centered and focuses on independence, autonomy, freedom and the choice of the individual, especially with regard to moral reasoning (Clement, 1996, p. 11-13; Gilligan, 1989, p.55; Larrabee, 1993, p. 3-5). Shakespeare (2000) concludes that the social problem of care, in which the rights of disabled care recipients are ignored needs to be balanced with the relational and moral aspects of care-giving and receiving: "empowered disabled people will achieve a better quality of life in a community in which each recognizes their responsibility to the other, rather than a world made up of competing and selfish individuals seeking to maximize their own advantage" (p. 64).

The work of disability studies scholars Nick Watson, Linda Mckie, Debra Hopkins Bill Hughes and Sue Gregory has been particularly influential in bridging the divide between feminist and disability perspectives on care (Watson et al., 2004; Hughes et al., 2005). Furthering the critique of care, Watson et al. (2004) argue that society does not pay enough

attention to the material and emotional labor of caregiving, especially as it relates to gender (p. 334). The authors highlight the fact that the IL movement for disabled people, which allows people to hire personal assistants (PAs), frames care as a business relationship between an employer and employee. Watson et al. argue that there are two key problems with such a utilitarian framework. First, it negates the “reciprocity and emotional involvement” (p. 338) that naturally occurs in caring relationships. Second, by focusing on the empowerment of the disabled person, the potential exploitation of the assistant is ignored (p. 338). The authors cite feminist scholars who have explored both the emotional and practical aspects of care work and described the ways in which this work is gendered. That is, rather than a social construction that upholds gender hierarchies, it is considered “natural” for women to take on the majority of caring responsibilities (p. 334). Building on the concept of “caringscapes,” a feminist framework that incorporates both the spatial and temporal to address the complex ways in which caring is conducted on a day to day basis, the authors introduce the term “needsapes.” Needsapes is a framework that acknowledges the fact that everyone at some point in their lives will need to be cared for and will also participate in caring. This acknowledges the ways in which needs are continually lived “through struggle, contradiction and flux” (p. 345). By highlighting the (inter) dependency and need that all people will experience at some point in their life course, needsapes becomes a “discourse bridge” between the often-competing disability studies and feminist perspectives on care (p. 331).

In a more recent article Hughes et al. (2005) address further possibilities for bridging the divide between the Disabled People’s Movement (DPM) and the feminist movement’s conceptions of care through a theoretical framework provided by post-feminist philosopher Luce Irigaray. The authors utilize Irigaray’s framework of the othered “female imaginary” to move beyond the gendered binaries established by the DPM and the feminist movement in regards to care (Hughes et al., 2005, p. 260). Watson et. al argue that care relations situate both care providers and care recipients in a “feminized social space.” “The feminization of care in a phallogentric culture makes participants in the caring relationship— regardless of gender identity – necessarily subordinate” (p. 260). By privileging the autonomy of the disabled person in the caring relationship and situating the carer as an employee, the authors argue that the DSM movement remains firmly situated in the dominant “masculine imaginary” (p. 268). “To be a carer or cared for – male or female, disabled or nondisabled in either role – is to be found wanting, to be other in relation to the masculine subject of modernity, to be reduced to ‘the other of the same’” (p. 265). As opposed to a marginalized other always defined “in relation to the masculine subject of modernity,” Hughes et al., argue that the “relational aspects of the caring process, its tactility, fluidity and embodied difference” have the potential to give the “othering and difference” that defines the caring relationship “social and symbolic representation” (Whitford, 1991a, p. 24, as cited in Hughes et al., 2005, p. 265). By situating the caring relationship as valuable in its own right, as separate from the masculine image, Hughes et al. open up opportunities for a more ethical and mutual relationship between the DPM and the feminist-movement’s understanding of care.

Feminist disability studies scholar Christine Kelly (2013, 2016) more recently illustrates the importance of accessibility in bridging the divide between disability studies and feminist theories of care by developing the concept of accessible care. She cites disability studies scholars' assertions that care is a potentially oppressive practice if the care is not directed by disabled people. Kelly acknowledges that "disability critiques of care also have limits as they often ignore the gendered nature of care work and the potential to oppress the individuals who work as care providers, many of whom are transnational and racialized subjects" (2013, p. 786). Kelly proposes accessible care, a fluid approach, as a conceptual framework through which to tease out the complexities of topics such as attendant services as well as other care issues, providing no easy answers (2013, p. 795): Accessible care, and the bridges it builds, offers an important contribution to disability and feminist scholars to move beyond both adversarial debate and a focus on 'common ground' to explore attendant services, and other care arrangements and issues, with a multifaceted approach situated in the realities of contemporary, globalized socioeconomic systems (2013, p. 796).

The flexibility of Kelly's framework builds many connections between experience and theory, acknowledges (even embraces) the tension between feminist and disability studies theories of care and positions discussions of care within transnational contexts. Contextualizing the care debate within our current socioeconomic situation helps to address the complexities and nuances of various approaches to care.

Feminist philosopher Eva Kittay has published particularly influential work on care in regards to people with profound cognitive disabilities. Kittay (2011) stresses that in many cases the relationship between caregivers and care recipients will remain inherently unequal. She argues that the IL movement's focus on autonomy fails to acknowledge that some people with disabilities, particularly those with profound cognitive disabilities, will never achieve autonomy. Kittay utilizes the term "ourselves" to encompass all of society, disabled and nondisabled, who will inevitably require care at some point in the life course. By seeing ourselves as always in relation to each other, Kittay acknowledges that people's sense of well-being is directly tied to both the giving and receiving of care (p. 54). Rather than focusing on autonomy, social policy and care practice can provide equal opportunity for a life of dignity and value to everyone as the end goal of justice. Kittay uses her daughter, who is an adult with a profound cognitive disability, as an example, stating "no accommodations, antidiscrimination laws, or guarantees of equal opportunity can make her self-supporting and independent" (p. 56). While Kittay does not completely ignore social policy, she suggests that the distribution of care resources demonstrates that feminist care ethics is not only suited to the private and intimate sphere but also to the public. She argues that a society that embraces a feminist ethic of care can begin to combat the "fear and loathing of dependency and with it, disability" (p. 56-57). However, many scholars would argue that the current transnational capitalist structures of society make the equal distribution of care resources impossible.

Materialist Structures of Care

Disability Studies scholar Nirmala Erevelles (2011c) analyzes the material conditions of citizenship for people with cognitive and profound disabilities, intervening in conversations about dependency, autonomy and rationality. She begins her discussion by criticizing humanist assumptions about citizenship that focus on rationality, autonomy and competence. Such assumptions about the human leave people with profound/cognitive disabilities on the margins of citizenship. “Notions of citizenship, rationality and autonomy are ideological categories that are constituted within the historical and material conditions of capitalism” (p. 164-5). The implication of Erevelles’ argument is an “alternative theorization of citizenship and citizenship education that is not just inclusive of difference, but is also transformative in its intent and practices” (p. 150). Erevelles challenges Kittay’s argument that the meaning of dependency “can be renegotiated outside the material conditions within which it is situated” (p. 160). She argues, rather, that the historical, materialist normative structures that enforce binaries such as rationality/irrationality and autonomy/dependence still exist, so they cannot yet be dissolved or transgressed as Kittay and some post-structural theories of citizenship focused on the discursive realm suggest (p. 164). Erevelles says, “I argue here that neither formal justice nor discursive interventions that deconstruct reason and privilege dependency over autonomy will prove to be emancipatory for people with severe/cognitive disabilities, because both reason and dependency are historically constituted within the laissez-faire economic structures of capitalist societies” (p. 160).

Erevelles challenges common interventions into the care debate by feminist, poststructuralist and disability studies scholars who suggest that the means to ameliorate the fear and hatred of disability and establish justice for all (including care givers and receivers) is to embrace the dependency that everyone experiences at some point in their life course. While such interventions may trouble discursive terms such as autonomy/dependency, these binaries remain foundational to the capitalist economic structures that shape our society.

Erevelles argues for a materialist transformative politic that will affect notions of citizenship, care and autonomy for both caregivers and care receivers. Erevelles challenges theories of relations between bodies as defining affective citizenship. She utilizes feminist scholar Sara Ahmed’s definition of “affective economies” in which emotions are crucial to locating “individuals with communities—or bodily space with social space—through the very intensity of their attachments” (Ahmed, 2004, p. 119, as cited in Erevelles, 2011c, p. 174). Erevelles suggests that Ahmed’s definition of affective economies potentially opens up possibilities for “a recognition of disabled subjects as social subjects located within reciprocal relationships” because “emotions (affects) do not reside in bodies but between bodies (author’s emphasis), and therefore emotions become the critical building block of most social relationships” (2011c, p. 174). However, Erevelles contends that Ahmed’s theories of affective economies ignore the “material context within which these relationships occur—a context that is instrumental in determining the nature of the relationship between caregiver

and care recipient” (p. 174). She argues that a feminist ethic of care that emphasizes interdependence in the domestic role, as well as theories that argue the ethic of care is exploitative to female carers, continue to rely on problematic humanist notions of autonomy.

Erevelles acknowledges the admirable work of Margrit Shildrick in feminist disability studies. However, she suggests that in regards to addressing an ethics of care in transnational contexts, Shildrick relies on a problematic dissolution of the dialectic between caregiver and care recipient. “Here, production is disassociated from the concrete activities of labor (the materiality of caring work) and reattached to affective relationships that emerge as a result of activities of consumption (receiving care).” As Erevelles notes, the collapse of the division between production and consumption “has profound implications for not only articulating an ethics of care, but also for articulating a transformative theory of disabled subjectivity” (2011c, p. 194). Yet, Erevelles argues that the idealism of Shildrick’s argument ignores the materialist conditions of poverty and unequal pay as well as the sexism and racism that continue to structure the caring relationship, particularly in the broader context of transnational, capitalist production (2011c, p. 194). To support her argument, Erevelles cites feminist scholar Julie Tarrant’s contention that “affective needs can be realized if and only if basic needs are met” (p. 195).

I agree with Tarrant’s argument to a point. However, in regards to people with psychiatric disabilities, in particular, the relationship between basic and affective (or emotional) needs is more complex. Many people with psychiatric disabilities, particularly those marginalized by racism and poverty as well, do need attention and care in regards to their affective needs in order to sustain the more basic, material needs of housing and food. These material needs may seem inconsequential to someone experiencing extreme mental distress that affects their emotions and the way they process their environment and interactions at a given time. However, I do argue that the push for self-determination, when it is not situated in the broader material contexts of racism, sexism and poverty, neglects a crucial portion of the population that struggles with mental distress. In the context of capitalist exploitation, self-determination becomes an option for the more privileged members of society. Erevelles concludes by arguing that we must always acknowledge the material conditions of transnational capitalism because these structures produce social difference through “the specific relations of production and consumption” (p. 97). It is only by acknowledging such material conditions that we can transform the body politic (p. 197). The oppressive material conditions of capitalism are also highly relevant to the care needs of people with psychiatric disabilities and must be further addressed.

Placing Psychiatric Disability in a Material Context

I agree with Erevelle’s argument, and expand her discussion to the specific material care needs of people with psychiatric disabilities, a disability category that is underexplored in care-giving and care-receiving scholarship. People with psychiatric disabilities are situated in a complicated and marginalized position in regard to citizenship, autonomy, dependency and

care. The social and political situation of people with psychiatric disabilities is complicated by gender, race and class status—often unacknowledged positionalities—that potentially contribute to a person’s mental distress. In many cases, as my review of self-determination and recovery literature in the mental health field demonstrates below, the responsibility for mitigating debilitating mental distress is placed on the shoulders of the individual, a responsabilization that ignores systemic and intersectional oppressions.

The recovery movement—which includes self-determination as a positive step forward—was started by consumer-survivors, both those with psychiatric disabilities who adhere to psychiatric treatment, and those who consider themselves survivors of psychiatric treatment they did not find beneficial. Recovery, through this movement, has come to be articulated as “a process in which people are able to live, work, learn, and participate fully in their communities” (Davidson, Rakefelt and Strauss as cited in Corrigan et al., 2012, p. 170). It is important to note that participation means choice as directed by the person with a psychiatric disability. Potential employment and community participation must revolve around the goals of the person in recovery. “Recovery may also imply the reduction or complete remission of symptoms” (Corrigan et al, 2012, p. 170).

As Erevelles argues, reliance on the affective economy and choice of care-receivers does not mitigate the oppressive power structures of the market economy “crisscrossed by the racial, sexual and transnational divisions of labor” (2011c, p. 175). It becomes nearly impossible to explore notions of affective needs, self-determination, dependency and care, without also addressing basic material needs (Erevelles 2011c; Torrant, 2002). Basic care needs are also provided primarily by women of color. Sociologist Mignon Duffy (2005) describes the increased racialization of low wage care, distinguishing between care that involves nurturance and a strong emotional component based on human connection, and care that involves reproductive labor: “Work that is necessary to ensure the daily maintenance and ongoing reproduction of the labor force” (p. 70). Building on the work of intersectional feminist scholar Evelyn Nakano Glenn, Mignon demonstrates, through a census data analysis that reproductive labor, which often includes the invisible labor of cleaning and cooking in both institutional and domestic settings, not only pays much less, but is primarily done by women of color (2005, p. 78). As Nakano Glenn (1992) points out, “Racial-Ethnic women are employed to do the heavy, dirty ‘back-room’ chores of cooking and serving food in restaurants and cafeterias, cleaning rooms in hotels and office buildings, and caring for the elderly and ill in hospitals and nursing homes, including cleaning rooms, making beds, changing bed pans, and preparing food” (p. 20). Building on these insights, I argue that attending to the basic material, and often gendered and racialized, care needs of people with psychiatric disabilities is an affirmative and necessary step in mitigating distress for both caregivers and care-receivers.

Materiality must be acknowledged, and systemic oppressions recognized, as a necessary aspect of self-determination and empowerment as a means of recovery. As I illustrated earlier psychosocial supports are also crucial for many people navigating severe

mental distress, so I do not want to necessarily suggest that the material needs should be met prior to the affective, emotional needs in many cases. However, as I will further illustrate in the following literature review, in many cases the scholars advocating for self-determination often frame managing housing, employment and community integration as a process of self-care (my emphasis) that is the responsibility of the person with a psychiatric disability, rather than a natural right that all individuals should have access to. The material provisions involved in care, such as housing, meals, access to supportive employment opportunities and assistance with child care, are crucial to supporting people navigating mental distress. More emphasis should be placed on providing those material provisions, rather than requiring, or even training, the individual with a psychiatric disability to manage those provisions on their own through the more abstract conceptions of self-determination.

Empowerment, Autonomy and Self-Determination

Self-determination, defined as the ability to make choices that determine the course of one's life, is currently being cited by many mental health researchers, as well as many people who identify as having a psychiatric disability, as a key component of recovery (Ryan & Deci, 2000). Mental health scholar Larry Davidson (2016) argues that this new movement in mental health treatment incorporating self-determination, peer supports and mental health navigators is key to recovery. Peer support refers to the training and hiring of people who are in recovery from severe mental illness to provide support for those currently receiving treatment in the mental health system. Health navigators are paid paraprofessionals that assist people with complex health needs to navigate the health system. Navigators often help people find available care options and provide support in the development of self-care (Davidson, 2016, p. 1094). Davidson acknowledges the important changes in government policy, such as the Americans with Disabilities Act (ADA), as a positive step toward empowerment and self-determination for people with mental illness. However, he contends that policy must be converted into action, which includes reducing stigma and discrimination, and implementing paid peer supports as well as other Medicaid supports to provide housing and training in self-care for people with mental illness. Davidson especially values attending to the choices and expertise of people with mental illness and their family members: "While stigma and discrimination continue to pose formidable obstacles, the foundations have been laid for mental health practice to come closer to resembling health care for other medical conditions" (p. 1091). Importantly, community inclusion should not be contingent upon recovery, but should be seen as a process that contributes to recovery (Davidson, 2016, p. 1092). Davidson cites various "recovery" supports prompted by the community mental health acts of the 1970's that include "supported housing and supported employment, along with the provision of community supports in such domains as education, parenting, socialization, and spirituality" (p. 1093).

Mancini (2008), too, argues that self-determination is the key component of any treatment plan that addresses the recovery of individuals with severe mental illness. Citing

Ryan and Deci (2000), he articulates the basic characteristics of self-determination—autonomy, competence and relatedness to others—arguing that autonomy is the most crucial component of recovery. “Although each need is important, I would suggest that instilling a sense of autonomy is the sine qua non of recovery-oriented practice” (Mancini, 2008, p. 359). Mancini describes current mental health practice as “traditional/paternalistic,” typically focusing on the rewards of adherence to a medication regimen and limiting choice for consumers to which medications will be used, not whether to take medication at all. Such care programs focus on “stabilization” “i.e. reduction in symptoms, absence of relapse” (Mancini, 2008, p. 362), as opposed to full integration in the community and the pursuit of a meaningful life aligned with the individual’s personal goals.

Davidson (2016) likewise argues that the key difference in more recent manifestations of the recovery model is that, “Instead of being prescribed as an intervention to ‘stabilize’ a patient in the community, supports are provided to enable the person to participate as fully as possible in a life of his or her choosing” (p. 1093). According to Davidson, care for people with psychiatric disabilities is a process of engagement with the person, their family members and others that will inevitably be a part of community integration:

“Recovery-oriented clinical practice should engage people with mental illnesses, their loved ones, and the others who support them (such as their employers and landlords) in planning and evaluating care. It also involves identifying and building on people’s strengths and the opportunities and resources that exist in their communities, and equipping and empowering people to play an active role in the management of their conditions” (Davidson, 2016, p. 1097).

However, as Corrigan et al. (2012) caution, current psychiatric practice relies on patient adherence to evidence-based practices, “including medication management, assertive community treatment, supported employment, family education and support, illness management and recovery, and integrated co-occurring disorders treatment” (p. 170). When people diagnosed with mental illness do not comply with the recommended treatment regimen, they are considered flawed and unable to follow a program that will be beneficial to their health and well-being (Corrigan et al., 2012, p. 169). Self-determination—defined by the authors as the ability to make choices, especially in regard to housing, employment, personal relationships, as well as “spiritual, educational, and recreational goals” (p. 170)—should be the new paradigm for treatment of people with severe mental illness. People with severe mental illness also have the right to make choices that may not benefit their health and well-being. “People with serious mental illness, like everyone else, should have the dignity to fail—that is, to make choices that ultimately are the wrong choices” (Corrigan et al., 2012, p. 170). The authors stress that it is important for mental health practitioners to value the goals of individuals with severe mental illness, even if these goals do not include symptom remission, “For example, having fewer symptoms of depression is a priority for one person, whereas having more meaningful friendships, regardless of mania, is essential for another” (p.

172).

A number of people with lived experience of mental distress echo these theorists, and cite self-determination as a key component of their recovery. Cynthia Ann Piltch (2016), for example, utilizes her own experience of severe depression and hospitalization to argue that self-determination is crucial to the recovery process. For Piltch, this includes access to information about treatment options and other resources, exposure to mentors who have lived experience of mental health challenges, as well as the opportunity to be engaged in meaningful activities:

“Mental health challenges are an assault on one’s self-esteem and self-confidence. I believe that these can be restored through the growth of one’s self-determination. Attention to these factors by service users such as myself, as well as the clinicians, peers, teachers, and loved ones in our lives can play an invaluable role in supporting our recovery and cultivating our self-determination” (Piltch, 2016, p. 79).

Jennifer Gerlach (2013) also draws on her experience of continued mental distress to discuss the loss of control as a result of her mental health conditions, but, more importantly, as a result of her treatment in psychiatric hospitals. “The individual's specific voice may go unheard, both literally and metaphorically. Further what a person has to say may be chalked up to their ‘issues’ or automatically deemed irrational or unreasonable. This can be incredibly disempowering” (p. 203). She asserts that it is only when she was able to gain a measure of control over her own treatment that she was able to experience the benefits of recovery, which she defines as, “An active process, emphasizing full integration into society at large” (2013, p. 204). As a result of various support groups and a camp for youth living with Tourette syndrome, Gerlach found she was able to see herself “not as a person who had been overcome by mental health conditions, but rather as someone who had these differences but could still flourish and even use these experiences to help others” (p. 206). For Gerlach, like Piltch, self-determination is key.

While self-determination may be important for any individual, and while I do not wish to devalue the insights of people with psychiatric disabilities who cite self-determination as a key aspect of their recovery processes, I contend we cannot advocate for self-determination without placing it in the broader materialist context of capitalist production. Transnational capitalism, as Erevelles (2011b) illustrates, produces social difference through specific ideologies and relations of consumption and production. Self-determination frameworks do not adequately address the material oppressions of racism, sexism and poverty enforced by capitalist production, oppressions which also contribute to a person’s mental distress.

The concept of recovery is a contested issue for many people who identify as mad activists and scholars. A number of people in this movement do not have the desire to recover a “meaningful life” in a mainstream community plagued by the oppressions of racism, poverty, heterosexism, and sanism (About, n.d.). Several of those in mad activist circles

would not advocate with Davidson (2016) for mental health treatment to adopt the practices of other medical conditions. This is a medicalizing view that pathologizes people who experience mental distress, and still suggests there is an inherent flaw in the way people with psychiatric disabilities navigate their experience (Beresford, 2016). While I admit that in many ways I am an example of recovery from severe mental illness, my own experience with self-determination is much more complex.

My Complex Relationship to Self-Determination

As a woman with bipolar disorder, I have made it a priority to attend to my mental health on a daily basis. I adhere to a medication regimen that includes an antipsychotic, an antidepressant and anti-anxiety medication to help with sleep. I attend weekly individual and group therapy, moderate my drinking and try to exercise at least three times a week. As a result of these efforts, I function quite well and could easily be considered a “poster child” for recovery. I am currently a PhD candidate in Disability Studies, and live on my own in Chicago, Illinois. I did not always function this well. I have been hospitalized for bipolar psychosis and have experienced two full-blown manic episodes that required I withdraw from my undergraduate program. A severe depressive episode later resulted in having to quit my job as a high school teacher mid-semester. Working to rebuild my life following these episodes, with the strong support of my immediate family and their resources, is not a new experience for me. I was lucky to receive excellent psychiatric care and benefit from improvements in anti-psychotic medications—namely increasingly less sedating side effects—which has allowed me to live my life as I choose, some would even say flourish.

While I acknowledge that self-determination is a strong component of my recovery, my positionality as a white, heterosexual woman from an upper-middle class, two parent household has been an even stronger component. My positionality has meant access to resources, including financial, but also flexibility in terms of time, should I require extra care. Disparities in diagnosis and treatment outcomes based on race, gender and socioeconomic status have received increasingly more attention in the past few decades, in particular for people living in rural areas or experiencing poverty: “...Many rural Americans have less access to mental health services than do other Americans, suicide rates vary with respect to a variety of demographic variables, and persons with the lowest level of socioeconomic status are estimated to be about 2 to 3 times more likely to have a mental disorder than are those with the highest level of such status” (Safran et al., 2009, p. 1962). Structural disparities in materiality matter to mental health.

Still, despite my current attention to my own care and functioning, there are days when I simply can't get out of bed, or when I have to focus on calming my racing thoughts and increased energy levels rather than structuring my day as I choose. When I am depressed, decision making becomes impossible, and the impulsiveness that characterizes my manic episodes must be acknowledged and managed, so I am hesitant to make any decisions during these times as well. These days now happen sporadically, as opposed to lasting weeks, months

or even years, but on these days, it is not self-determination that keeps me going. I have a strong, supportive disability community in Chicago, and I have told my friends in this community that during these times, when attending to my basic care needs seems impossible, what I really need is someone to bring me dinner, or walk with me to get food. Any food preparation, much less clean up, is an overwhelming task. The fact that I cannot prepare a meal or wash my pile of dishes makes me feel even more overwhelmed and dejected; the basic care my friends provide of bringing me food and offering to clean up my apartment a bit is immensely helpful.

Neoliberal ideologies, policies and governance structure in the global north include the marketization and responsabilization of all aspects of life while concealing how capitalist production and consumption demands productivity at all times (Larner, 2000). Many scholars who discuss neoliberalism also emphasize the concepts of choice and personal responsibility inherent in the framework. Neoliberal models of choice, create a regime of violence that is not necessarily coercive but instead appears as if we ‘can be all we want to be’ and in fact should aspire to do so, without taking into account the restrictions put forth by oppression due to racism, class inequality, gender/sexuality and mental difference (O’Leary & Ben-Moshe, forthcoming).

As such, it is during the episodes I describe above that I embody Rosemarie Garland-Thomson’s concept of “misfitting.” Garland-Thomson (2011) explains that the misfit is a mismatch between embodiment and environment. The concept of misfitting firmly lodges oppression in material conditions “rather than social attitudes or representational practices” (p. 593). Fitting is a phenomenology of privilege that confers social capital and allows one to “exercise the rights of citizenship in democratic orders” (p. 596).

Even when I am not necessarily symptomatic, I identify as bipolar, disabled or mad, depending on the context, and I acknowledge that this identity is a crucial part of how I navigate the world and build relationships with others. My disability identity is not just a small part of who I am, but in many ways, defines me, the choices I make, the relationships I choose to build, as well as the scholarship, activism and advocacy I choose to engage with. As a result of my psychiatric disability, or madness, I do not always possess the phenomenology of privilege that fitting confers. This experience of misfitting is not static for me and, in some contexts, I do fit quite well. Still, my experience of misfitting in certain contexts affects my social capital and status on the hierarchy of production and efficiency dictated by the capitalist structures of our society. The life of a PhD student allows flexibility, but most jobs in the marketplace that provide a stable income and insurance do not. I went into teaching for the promises of stability and excellent insurance that would cover my psychiatric appointments and expensive medications. However, my bodymind was not equipped to be fully functioning from 8am to 5pm, five days a week for an entire school year, even with the promise of a summer vacation. In that sense, my choices for employment are limited. I opted for the flexibility of academia, which is working out well thus far. Academia remains a neoliberal institution that some would argue is also embedded in “genocidal” “regimes”

(Rodríguez, 2012, p. 810). Tenure track academic jobs demand a high amount of productivity, but also entail “surveillance, discipline and low wage punishment” for those in more marginalized positions (Rodríguez, 2012, p. 811). Still, while the flexibility of scheduling does require intensive time management skills, it also does not necessarily require that I be fully functional for up to 10 hours a day, five days out of the week. In important ways I can structure my days according to my own choice, and if I am not functional one day it generally does not require I call into work and feign a migraine, only that I make up the work when I can. I also acknowledge that my misfitting has been an important component in redefining how I view my own agency. Garland-Thomson (2011) discusses the benefits misfitting can confer in aspects of identity formation and political activism, despite the obvious advantages of navigating our current world with ease:

“In this sense, the experience of misfitting can produce subjugated knowledges from which an oppositional consciousness and politicized identity might arise. So although misfitting can lead to segregation, exclusion from the rights of citizenship, and alienation from a majority community, it can also foster intense awareness of social injustice and the formation of a community of misfits that can collaborate to achieve a more liberatory politics and praxis” (Garland-Thomson, 2011, p. 597).

I love the disability community I now belong to, and I choose to spend my time engaged with intense discussions of what it means not to fit. When I presented at the Mad Studies stream of the Lancaster Disability Studies Conference in England, I left feeling an exhilaration and energy that only comes from engagement with a community of people who experience misfitting in many of the same ways I do and, thus, share many of the same sorts of subjugated knowledges, in this case the crazies and mad. Being part of the knowledge and praxis that such a community generates is intensely valuable to me and is something that I know many people in my life will never experience, namely my immediate family, my parents and my sister. While I love them dearly and am so grateful for the endless love and support they have given me, they admit that their bodyminds do represent the norm, and, in many ways this has made life much easier for them. This is something I will never understand, or embody, and I find myself grateful for that as well.

Self-determination and recovery dictate that I should choose to engage with society in “meaningful” ways. But what currently gives my life meaning is to take part in a community of resistance against the heterosexist, racist, ableist and sanist aspects of the world that I wish to transform. I do not necessarily live my life with ease, but I do live it with agency, and I think my disability identity is a key component of this.

I also possess privilege that has allowed me to live my life with a particular form of agency emerging within global north disability scholarship and community. My status as white, heterosexual and middle-class also affords many opportunities to engage what is currently framed as recovery. The dominant pathways to self-determination and recovery I introduced above are not uniformly available to everyone in our society, especially those who

are marginalized within the intersectional oppressions of race, gender and class status. Our society is designed for certain people to be successful and this includes only a portion of those living with mental health issues. Until systemic structures of oppression are transformed, self-determination as a gateway to recovery will only benefit those who already possess social and economic capital in other aspects of their identity.

My aunt, my mother's sister, is an extremely sensitive and amazing woman who has struggled with various forms of mental distress her entire life. I tell her story here as someone known intimately and I feel that many of the opportunities for care that I am advocating here would benefit her immensely, as she is often blamed for her own struggles and faulty choices. By telling her story I wish to reinforce my argument that neoliberal notions of productivity, choice and responsibility are highly embedded in conceptions of self-determination. What often gets ignored are the material structures of poverty, racism and sexism that actually make self-determination impossible for many. My aunt gets angry when anyone calls her crazy, as she does not see this as a potentially politicized identity, and to be fair, most of the people in her life are utilizing the label in a negative and dismissive way. Still, my aunt's mood swings, angry outbursts, regular tearful episodes and days when she cannot get out of bed, have made pursuing the functions of daily living very difficult for her. She may not identify as crazy, but she does often embody Garland-Thomson's definition of misfitting. The material conditions of the world in which she lives are not often conducive to her highly sensitive nature. As a result, she struggles quite a bit. She is a hairdresser living in poverty and a single mom. Her devotion to her son is nothing short of remarkable, but she was tasked with raising him with very limited resources, while also contending with her own navigation of an inaccessible world. Sexism also figures strongly in her life. Her son's father provided some financial support, although this was not always steady. He would show up on the weekends to take his son fishing or camping, but the majority of the child-rearing fell to my aunt. Her options for respite, treatment and support are limited. Her general practitioner, through Medicaid, prescribed a daily dosage of Prozac to ease her struggles a bit. Prozac is a very old drug with many side effects and while it treated her low moods and obsessive tendencies it also caused increased drowsiness and a propensity to let many things in her life slide, as she simply found herself not caring anymore. She had no additional supports in terms of therapy to adjust to this change, but was still expected to manage these issues on her own while attending to the daily tasks of living, working and helping to support her son, who is now 21. My aunt went off the medication and continues to regularly struggle. I do not blame her struggles on a lack of self-determination or an inability to take responsibility for her life, but on the structural conditions of poverty and sexism that make recovery very difficult for her. Should she be provided with supports to ease the material conditions of poverty, I think she would have more time and resources to attend to her own care needs, and find some ways to ease her anxiety and advocate for herself. This might include someone to clean her trailer, provide more stable and affordable housing, make her meals and offer assistance in raising her son. In advocating for self-determination as the primary means of recovery from mental distress, we cannot neglect the gendered material oppressions that only allow the most privileged to

embrace self-determination. Self-determination as it is currently framed without context, reifies class, gender and racial oppressions as individual matters, offering opportunities only for those willing and able to take them.

Many of the things I do to promote my self-care and ease my stress implicate me in a gendered and racialized labor force. I hire people to clean my apartment once a month through a company that charges a flat fee for a two-hour cleaning. I have had a variety of people clean my apartment, all of them women of color. Duffy (2007) studied the demographics of an increasingly racialized labor force that does the bulk of care involving cleaning and food preparation, what she describes as “non-nurturant reproductive labor” (p. 315). “In 1900, all groups of women were heavily overrepresented among non-nurturant labor. Black women’s enormously disproportionate representation among domestic workers is reflected in a relative concentration of 6.66 in non-nurturant reproductive labor,” Duffy’s figures represent, “the ratio of a group’s representation in a particular sector relative to that group’s representation in the labor market as a whole (Amott & Matthaei, as cited in Duffy, 2007). A value of 1 indicates perfectly proportional representation, values more than 1 indicate overrepresentation and values less than 1 indicate under representation” (Duffy, 2007, p. 329). She notes the shifts in these demographics as of the year 2000, with the concentration of white women in these positions decreasing to 1.04, a nearly proportional representation compared to their representation in the labor market as a whole. The concentration of Hispanic women rose to 2.00, while, Black women and Asian/Pacific women remain overrepresented in these sectors with respective rates of 1.41 and 1.28 (p. 330). These women’s situations illustrate that the labor required for self-care and the type of care I am advocating for, namely attention to basic needs, is something that many women of color perform as their daily jobs. My reliance on this labor force is most certainly an example of me “fitting” rather than “misfitting” into the dominant structures of society. The basic care requirements fall on the backs of women of color, indicating that the care is gendered and racialized. The material constraints of this situation do not allow for many women of color to address their own care needs when they are experiencing mental distress, for example. This affects not just women of color in the global north, but also those migrating from the global South to the global North, in many cases to perform underpaid and feminized care work. Many scholars have addressed the increasing transnational migration of a feminized labor force from the global South to the global North as a result of globalization and the international reach of a capitalist market system (Barker & Feiner, 2010; Petrozziello, 2011; Yeoh, Huang, & Willis, 2000). A transformative politics of care that addresses the basic needs of women of color, who, based on our current framework of capitalist production are relegated to attending to the needs of others, is necessary if we are to continue to promote self-determination as a pathway to recovery from mental distress.

Conclusion

Care for people with disabilities is a widely debated topic, as evidenced by the

increasingly extensive literature. However, the specific care needs of people with psychiatric disabilities present a different dilemma in regard to care that is not always acknowledged in care literature. Much like episodic physical disabilities, care needs for persons with psychiatric disabilities are not constant or predictable. As opposed to many episodic physical disabilities, however, where the need for care is acknowledged, people with psychiatric disabilities are expected, through self-determination, to attend to their own care needs. I function quite well as a person living with a psychiatric disability a lot of the time, but there are certainly times when I require more support in getting my basic needs met. I have argued in this paper that self-determination as a necessary path to recovery needs to be placed in the broader material context of capitalist production that continues to marginalize certain populations based on their gender, race and class status. A feminist ethic of care is a useful step forward as it acknowledges relationality and connectedness, rather than privileging autonomy and independence through self-determination frameworks. However, as Erevelles argues, care needs, including the needs of people with psychiatric disabilities, must be placed in the materialist context of current societal structures, structures that are upheld by notions of autonomy and independence. The way our society is currently structured allows only the privileged to embrace self-determination as a necessary path to recovery. Placed within the broader context of transnational capitalism, a system that creates and sustains social difference, it becomes apparent that self-determination is not an option for everyone in our society who is managing mental distress. The complexity of material constraints need to be acknowledged and addressed, and the basic gendered and racialized labor of cooking, cleaning, raising children and securing stable housing, needs to be attended to and acknowledged while we advocate for self-determination as a viable path to recovery for everyone.

Meghann O’Leary is a PhD candidate in Disability Studies at the University of Illinois in Chicago. She holds a Master’s Degree in Special Education from the University of New Mexico and a Bachelor’s Degree in English Literature from Vassar College. Her research interests include the intersections of Mad Studies and Disability Studies as well as providing an intersectional lens to the study of life writings by women diagnosed with psychiatric disabilities. Her current work involves placing life writings by women with psychiatric disabilities in a historical, cultural and political context to frame the relationship between disability, madness and gender.

References

- About. (n.d.). Retrieved from <https://recoveryinthebin.org>.
- Barker, D. K., & Feiner, S. F. (2010). As the world turns: Globalization, consumption, and the feminization of work. *Rethinking Marxism*, 22(2), 246-252.
- Beresford, P. (2016). The role of survivor knowledge in creating alternatives to psychiatry. In J. Russo and A. Sweeney (Ed.), *Searching for a Rose Garden: Challenging Psychiatry, Fostering Mad Studies* (pp. 25-34). Monmouth, Wales: PCCS Books Ltd.
- Clement, G. (1996). *Care, autonomy and justice: Feminism and the ethic of care*. Boulder, CO: Westview Press.
- Corrigan, P. W., Angell, B., Davidson, L., Marcus, S. C., Salzer, M. S., Kottsieper, P., Larson, J., Mahoney, C. A., O'Connell, M. J., & Stanhope, V. (2012). From adherence to self-determination: Evolution of a treatment paradigm for people with serious mental illness. *Psychiatric Services*, 63(2), 169-173.
- Davidson, L. (2016). The recovery movement: Implications for mental health care and enabling people to participate fully in life. *Health Affairs: At the Intersection of Health, Health Care and Policy*, 35(6), 1091-1097.
- Duffy, M. (2005). Reproducing labor inequalities: Challenges for feminists conceptualizing care at the intersections of gender, race and class. *Gender and Society*, 19(1), 66-82.
- Duffy, M. (2007). Doing the dirty work: Gender, race and reproductive labor in historical perspective. *Gender and Society*, 21(3), 313-336.
- Erevelles, N. (2011a). Disability as 'becoming': Notes on the political economy of the flesh. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic* (pp. 25-63). New York, NY: Palgrave MacMillan.
- Erevelles, N. (2011b). (Im) material citizens: Cognitive disability, race, and the politics of citizenship. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic* (pp. 25-63). New York, NY: Palgrave MacMillan.
- Erevelles, N. (2011c). The "other" side of the dialectic: Toward a materialist ethic of care. *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic* (pp. 173-197). New York, NY: Palgrave Macmillan.
- Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, 26(3), 591-609.

- Gerlach, J. (2013). Jerk: A tic-inspired view of the self-determination paradox in our mental health system. *Journal of Progressive Human Services, 24*(3), 200-208.
- Gilligan, C. (1989). Mapping the moral domain: New images of self in relationship. *Cross Currents, 39*(1), 50-63.
- Glenn, E. N. (1992). From servitude to service work: Historical continuities in the racial division of paid reproductive labor. *Signs: Journal of Women in Culture and Society, 18*(1), 1-43.
- Hughes, B., McKie, L., Hopkins, D., & Watson, N. (2005). Love's labours lost: Feminism, the disabled people's movement and an ethic of care. *Sociology, 39*(2), 259-275.
- Kelly, C. (2013). Building bridges with accessible care: disability studies, feminist care scholarship and beyond. *Hypatia, 28*(4), 784-800.
- Kelly, C. (2016). *Disability politics and care: The challenge of direct funding*. Vancouver, BC: UBC Press.
- Kittay, E. (2011). The ethics of care, dependence and disability. *An International Journal of Jurisprudence and Philosophy of Law, 24*(1), 49-58.
- Larner, W. (2000). Neoliberalism: Policy, ideology and governmentality. *Studies in Political Economy, 63*(1), 5-25.
- Larrabee, M. J. (1993). Introduction. In M. J. Larrabee (Ed.), *An ethic of care: Feminist and interdisciplinary perspectives* (pp. 310). New York, NY: Routledge.
- Mancini, A. D. (2008). Self-determination theory: A framework for the recovery paradigm. *Advances in Psychiatric Treatment, 14*(5), 358-365.
- O'Leary, M. & Ben-Moshe, L. (Forthcoming). Homage to Spencer: The politics of "treatment" and "choice" in neoliberal times. In L. Costa, P. Beresford and A. Daley (Ed.), *Madness, Violence and Power: A Radical Anthology*.
- Petrozziello, A. J. (2011). Feminised financial flows: how gender affects remittances in Honduran-US transnational families. *Gender & Development, 19*(1), 53-67.
- Piltch, C. A. (2016). Speaking out: The role of self-determination in mental health recovery. *Psychiatric Rehabilitation Journal, 39*(1), 77-80.
- Price, M. (2015). The bodymind problem and the possibilities of pain. *Hypatia, 30*(1), 268-284.

- Rodríguez, D. (2012) Racial/colonial genocide and the “neoliberal academy:” in excess of a problematic. *American Quarterly*, 64(4), 809-813.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68 –78.
- Safran, M. A., Mays Jr, R. A., Huang, L. N., McCuan, R., Pham, P. K., Fisher, S. K., ... & Trachtenberg, A. (2009). Mental health disparities. *American Journal of Public Health*, 99(11), 1962-1966.
- Shakespeare, T. (2000). *The social relations of care*. In S. G. Gail Lewis, John Clarke (Ed.), *Rethinking Social Policy*. London: SAGE Publications.
- Watson, N., Mckie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter) dependence needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology*, 38(2), 331-350.
- Yeoh, B., Huang, S., & Willis, K. (2000). Global cities, transnational flows and gender dimensions: the view from Singapore. *Tijdschrift voor economische en sociale geografie*, 91(2), 147-158.