REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL
Volume 13
Issue 4

Editorial

Is this a Marriage or a Carriage?

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RDS Editor-in-Chief

Please forgive the pun in the title. Thoughts of "care" and "marriage" were floating around in my head as I was floating around in the pool. I think about marriage a lot, partially because I am married (surprise, surprise), and partially because in my insecure moments (or when I am mad at my husband) I obsess over the role of care in my marriage. Who is taking care of who? What is "normal care" in our marriage, and what is "crip care"? I am deafblind so I don't drive (not legally anyway). Am I asking too much when I ask my husband to do all of the driving for our family? My grandmother was not disabled and she didn't drive. This was not atypical of her generation, as driving was often considered a "man's job." Was my grandfather a "carer" of my grandmother because he drove her everywhere? Or a chauffeur? Or a chauvinist?

Other things I have trouble doing independently include killing cockroaches, fixing leaky faucets, setting rat traps, scrubbing really dirty pots, barbecuing, cleaning the oven, climbing onto the roof, understanding the point of football, fixing my computer, and talking to my father-in-law. This is an impressive list of "man jobs" that somehow my liberal upbringing during the sexual revolution failed to teach me, so I do depend on my husband for these essential tasks. And no one would question his doing these tasks in his role as "husband." Just as no one would question my doing the cooking, laundry, household management and primary childcare in my role as "wife." I know plenty of women whose husbands do the cooking because hubby enjoys cooking. But if hubby does the cooking because his wife is disabled, that makes him a "carer" instead of "a guy who likes to cook." If a wife does the cooking, whether her husband is disabled or not, she is just doing her job as a wife.

I recently met a couple where the wife has become significantly physically disabled during the past year. By all appearances the husband has taken on his new role as "carer" with grace, with caring, in fact. But it was also apparent that they still struggle with frustration at new barriers, with the things that the wife is no longer able to do. The "new normal" is hard to face, especially since society takes it for granted that a marriage is comprised of two people who will share equally in daily living tasks. That is an ideological view in a world where women still take on an unequal amount of household and childcare responsibilities even when they also take on an equal amount of financial responsibilities. Where is the help with childcare, transportation, cooking, bathing, and grocery shopping that this family with a single wage earner and a disabled family member needs? It does not exist. These duties are seen as the family's responsibility, and if one member chooses to be a carer rather than dumping his useless wife off at the local multi-bed facility, that is his problem.

As I read the articles in this issue's forum on "Cripping Care" I found myself stunned by the obvious but not-talked-about-enough parallels between feminist theory and disability theory. I hope the forum will also change your thinking about how we view care.

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Volume 13
Issue 4

Research Article

Cripping Care: Care Pedagogies and Practices

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> "…Any radical pedagogy must insist that everyone's presence is acknowledged" (hooks, 1994, p. 8).
>
> "…To begin always anew, to make, to reconstruct, and to not spoil, to refuse to bureaucratize the mind, to understand and to live life as a process—live to become…" (Freire, 1993, p. 98).
>
> "Disabled people have never demanded or asked for care!" (Wood as cited in Thomas, 2007, p. 107).

Any attempt to understand or take up "care" in its lived, philosophical and political aspects is a slippery affair. If nothing else, feminist, disability and care scholars and activists converge around the vitality of care. Care is fundamental to being and becoming human together. It encompasses the intimate, fleshy and mundane exchanges between bodies engaged in everyday affects and acts—of giving and receiving, of living and growing, of teaching and learning—that are fraught with ethical complexity. Although "predominantly regarded as an inferior practice to education" (given its associations with "feminine" nature, affect and dependency) (Gibbons, 2007, p. 125), care is central to all human life, and as such, must be acknowledged as interconnected with and of equal importance to education (Hobgood, 2015; Wood, 2015). Like education, care is particular, highly contextual, and political. From our starting supposition that care is essential to life, and grounded in a feminist disability studies perspective, this special forum *Cripping Care: Care Pedagogies and Practices* engages care's complexity in relation to multiple intersecting issues: (1) the rights of persons with disabilities and chronic illnesses to support; (2) dawning public knowledge about the violence of institutional care and custody regimes against young, aging, disabled and racialized persons (including in colonial institutions); (3) critiques from feminist, disability and Global South scholars of care's oppressive tendencies; and (4) the implications of neoliberal care regimes for the world's disabled and aging populations (see, for example, Aubrecht & Krawchenko, 2016; Williams, 2011). Indeed, these complexities of care have increasingly come to occupy a central place on scholarly and global policy agendas (Yeandle et al., 2017).

Critical care theorists raise fundamental moral questions about the needs, rights, responsibilities, and power of carers and those who need support; questions whose philosophical and political moorings have much in common with those grounding critical pedagogy (Monchinski, 2010; Tronto, 1993). Care scholars have not yet considered how care relations—and the teaching and learning that occur through care exchanges—are necessarily pedagogical. The pedagogic features of care remain overlooked and undertheorized despite the general orientations of the fields of education and social care to the centrality of relationships in the daily activities of living. This is especially curious given that pedagogy scholars in diverse areas ranging from environmental education (Goralnik et al., 2012) to early childhood and post-secondary education (Magnet et al., 2015; Wood, 2015) have argued for adopting an ethics of care alongside that of justice, and for closely attending to care as integral to any critical, disability or other social justice pedagogy.

In this forum, we build on the critical pedagogical insight that practices of teaching and learning rooted in Eurocentric humanist systems of education delimit ways of knowing/what counts as knowledge (Freire, 1993; hooks, 1994). We assert that care relations grounded in similar logics likewise constrain what can be known about and across difference. Insofar as care relations position the carer as agent and those who need support as acted upon, hegemonic care practices—like Freire’s “banking system” of education and hegemonic teaching practices—override more open-ended, processual and potentially fertile exchanges across human differences, as well as between human and non-human life and the animate and inanimate world. We make the case that care, like education, is not simply an investment that yields losses or gains. It is not a resource that owners can “deposit” or “withdraw”. It is, rather, a reciprocal relationship that requires the active—though not necessarily the equivalent or equal—involvement of all present in care exchanges.

*Cripping Care: Care Pedagogies and Practic*es asserts a new turn in feminist disability studies to advance care conversations by (re)orienting to care as critical pedagogical terrain. To “crip” care as vital terrain for teaching and learning means “to shake things up, to jolt people out of their everyday understandings of bodies and minds, of normalcy and deviance” (Kafer, 2013, p. 15; also see Sandahl, 2003). Care scholars have recently begun to recognize the value of a cripped approach to care. Sally Chivers (2017), for example, crips care advice literature within the context of neoliberal austerity thinking “to politicize, activate, and understand marginalized body-minds” (p. 7) in ways that (re)value care and disability. In this special forum, we turn the tables and open the terrain of care itself as necessarily pedagogical, replete with lessons about the self, other and world including histories of power and marginalization, resistance and reclamation, normalcy and deviance, affect and violence, fleshy sensuality and dehumanizing systems. Cripping care as pedagogical is a radical rethinking of—and learning from—the fraught knot of “normalcy and deviance” (Kafer, 2013, p. 15) at the core of care relationships and ‘caring’ regimes. Our approach to cripping care recognizes care as fundamental to life. It also recognizes how caring relationships characteristically carry a jolting, perhaps irresolvable paradox—that of transgressive possibility and coercive constraint, intimate inter-dependence and constraining power, love, and violence. In this, care seeks to normalize or cure while also holding possibilities for individual and collective transgression and freedom (Douglas, 2010, 2016; Kelly 2013, 2016, 2017).

Disability perspectives have long challenged common and scholarly approaches to care, insisting on the ways that care is intertwined with patronizing attitudes and behaviours that can be used to oppress those who require support or work in the field of care. Most alarmingly, claiming to “care for” people with disabilities as a socio-medical category has justified segregated education and living arrangements, institutionalization, abuse, sterilization, painful and ineffective treatments, and many other harms to disabled bodies (Ben-Moshe, Chapman & Carey, 2014; Kelly, 2016; Rice, 2014). These harms are often uncomfortably motivated by sincere caring intentions and concern. In the Global North, Independent Living approaches question the conflation of disability with dependency and the need for care, and emphasize the right to autonomous personhood, favoring terms like “help,” “support,” or “assistance” rather than “care” (Shakespeare, 2006). At the same time this disavowal of the term care is not a disavowal of fundamental social and health services required by many to participate in everyday activities. Scholars working at the intersection of disability, feminist and other critical approaches to care have more recently issued calls for disability studies approaches that center interdependence in ways that bring the perspective of disabled people and the force of political economy to the fore, taking into account gendered, racialized, and classed aspects of care work while sustaining earlier disability critiques of the realities of violence against disabled persons within care relationships (Douglas, 2016; Kelly, 2013, 2016, 2017).[1] We are called to interrogate the needs, interests, and rights of those who require support and those who provide it (both human and non-human), the policy infrastructure that governs the uniquely public/private spaces of care, as well as the deeply embedded cultural references that our understandings of care are steeped in. There is also much relational space among these experiential, policy and symbolic arenas, spaces that are perhaps the most difficult to explore.

The scholarly articles that make up this forum on cripping care attest to the growing urgency for critical disability studies to interrogate care’s complexities and excavate the pedagogical possibilities (Rice et al., 2016; 2017) of intimate and structural care relationships in the service of disability emancipation (Viscardis et al., under review; Rice et al., forthcoming). Together, these four articles crip understandings of care relationships as non-objectifying, unscripted and immeasurable but also finely attuned to power in its myriad aspects, including its aesthetic, sensual, fluid, non-material, affective, non-linear and spontaneous dimensions. The forum crips care as not only fundamental to life, but also divergent and potentially emancipatory, offering glimpses of becoming human together in relationships that move beyond neoliberal, ableist, capitalist, and colonial modes of power, expected subjectivities and humanist notions of the human. Together, the articles exemplify the radical and engaged pedagogy Bell Hooks (1994) describes as a “practice of freedom,” one that centrally involves critique as well as passion, creativity, excitement and caring exchanges that implicate us all in the call to critical reflection about ourselves, the other and the world. This locates the forum—and intervenes in care conversations—at the intersection of disability studies, feminist and other critical approaches to pedagogy and care and inserts a distinctly feminist crip approach to care practices.

A Distinctly Feminist Crip Approach to Care

A distinctly feminist crip approach to care forged through this forum (re)orients those in care relationships—mother and child, human and animal, teacher and student, mad activist and family member—as relationally constitutive learners/teachers who generate knowledge through approaching the care exchange as a teaching and learning encounter. Each article attends to the intricate dance within relational space, along with what might be learned from one another through this pedagogical focus about non-normative embodied life, power and remaking care anew. In this approach, crip theory interweaves with feminist disability studies and other critical approaches to open up conversations about disability and care in ways that are both generative as well as radical, working across tensions around identity politics that can reify difference and polarize care conversations along transnational, race, class, gender and sexuality lines. As such, the forum traverses interdisciplinary terrain including disability, feminist, mad, new materialist, and transnational feminist and educational scholarship. “Crip,” like “queer,” Kafer tells us, “examine[s] how terms such as ‘defective,’ ‘deviant’, and ‘sick’, have been used to justify discrimination against people whose bodies, minds, desires and practices differ from the marked norm” (2013, p. 17; also see McRuer, 2006; Sandahl, 2003). Collectively, the authors offer fresh perspectives on disability and care that contest normalizing, often violent care regimes and practices—including normalizing therapies or institutionalization—under the guise of care structured by ableist colonial logics, patriarchy and neoliberal capitalism. Critically engaging the paradox of care, cripping care as put forward in this forum foregrounds the agency, experience and value of disabled persons, and has implications for remaking social policy, support and services in ways that do not foreclose disabled persons’ access to life or eschew all those in caring relationships.

In her contribution, “What Is a Service Animal? A Careful Rethinking,” Margaret Price opens new questions about how hierarchies and histories of human and non-human difference are forged and maintained. Through her intimate first-person exploration of the complexities of care between human and animal in Canada and the United States, Price reveals how the governance of service dog regulations overrides the affective and ambiguous elements of caring relationships, making requisite animal (and human handler) “fitness” in ways that expel—or at least highly regulate—disability and difference, whether human or animal. Bringing old and new materialisms together in an approach she calls “crip spacetime,” Price crips the ways we might think about how human/animal and object/affect become together: “…There is no clear distinction between ‘person’ and ‘environment’; rather, disabled life (and death) become through a complex dance of space, time, objects, texts, and organisms.” Price foregrounds both the sensuous pleasures and material constraints and violence that echo throughout in caring relationships. In her commentary, she offers a rethinking through which we might come to learn differently about the caring relationships, histories, objects and affects that compose our everyday worlds.

Nandini Ghosh and Supurna Banerjee crip understandings of care and disability within the context of the Global South in their article, “Too Much or Too Little? Paradoxes of Disability and Care Work in India.” They examine mother-daughter relationships in three rural villages in India for girls with profound physical and/or cognitive disabilities. The authors surface the intimate ways care is lived and negotiated by mothers and daughters in these contexts of severe poverty and patriarchy where community, medical and rehabilitation services are in short supply, and boundaries between duty/burden and love/violence blur in the everyday. Ghosh and Banerjee challenge readers in the Global North to question tendencies toward familiar and ‘too-tidy’ critiques of care as oppression or as ‘natural’ delight. Care, as the authors show, is a complex relationship that is often both, simultaneously. Through the sheer physicality and intimacy of their descriptions of care, Ghosh and Banerjee reframe the social model of disability alongside a politicized ethic of care within the specifically communitarian ethos of three rural villages. They call for culturally specific analyses that centre the tensions (Kelly, 2017) of care— autonomy/dependence, impairment/disability, public/private, individualism/communitarianism, and care/violence.

In “Cripping Care for Individuals with Psychiatric Disability: Looking Beyond Self-Determination Frameworks to Address Treatment and Recovery,” Meghann O’Leary crips conversations about self-determination, care and psychiatric disability. Through an extensive literature review, O’Leary shows how dominant care theories and mental health discourses of self-determination do not address the ways in which the material conditions of transnational capitalism, including the intersecting oppressions of race, class and gender, produce unequal opportunities for self-determination and recovery. Working from a feminist materialist disability studies perspective, O’Leary employs autoethnography to excavate what she calls the “often-unacknowledged material conditions that contribute to mental distress.” By surfacing the intimate ways in which this process unfolds in her own life, O’Leary calls for a radical re-visioning of care politics that addresses intersecting oppressions and theorizes care more completely.

Susan Baglieri and Jessica Bacon’s article, “Teaching and Care: Cripping Fieldwork in Teacher Education,” moves us to (re)consider institutionalized forms of care within public education in the United States. The authors describe part of a larger research study that aims to crip teacher education and build access to higher education for intellectually disabled adults. They focus on a “cripped” fieldwork experience with teacher candidates, which hosted adults labelled as intellectually disabled who opted (as part of their day program options) to attend college once a week. Drawing on the social model of disability and Noddings’ concept of ethical care (1984), the study crips normative understandings of care within public educational contexts that characterize difference in terms of deviance and disabled persons as the “benefactors” of professionalized and paternalistic remedial care. In weekly reflection journals, teacher candidates come instead to explore care as a form of reciprocity that centers teaching and learning and blurs binaries. From within reciprocal relationships—albeit ones where power and vulnerability is unevenly shared— teacher candidates come to embrace the non-reductive and fundamental worth of all within relationships, and to forward radical notions of inclusion and care.

The articles in this special forum *Cripping Care: Care Pedagogies and Practices* assert a radical new care politics that pushes the borderlines of theorizing and praxis. Together, they crip the now-familiar notions of care in disability and feminist studies as business exchange, oppressive relation or romanticized bond without denying care's sensual pleasures, labour and pains, ethical questions or political economy. Cripping care as dynamic pedagogical terrain brings relationality and power to the center, and breathes life into care as a mutable, symbiotic living bond, as reciprocal, though not necessarily symmetrical, vulnerability that affects us all (Rice & Mundel, forthcoming). In its concreteness, care as relationship is also ineffable, open to the uniqueness and difference of another to whom we are intimately tied (van Manen, 1990, p. 142-156). This involves care—giving, receiving, and giving back; knowing, unknowing and discovering; creating, teaching and learning about self, each other and the world anew.

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Carla Rice is Professor and Canada Research Chair at the University of Guelph in Ontario, Canada specializing in embodiment/subjectivity studies and in arts-based/research creation methodologies. She founded *Re•Vision: The Centre for Art and Social Justice* as a leading-edge arts-informed research creation centre with a mandate to foster inclusive communities, well-being, equity, and justice. She has received awards for advocacy, research, teaching and mentorship, published 4 books, 69 papers, 26 chapters, and 13 reports, and produced over 400 films. She currently contributes to nine research grants, including as co-director/PI of *Bodies in Translation: Activist Art, Technology and Access to Life*, a Partnership Grant that engages 23 community organizations and universities to cultivate d/Deaf, disability, mad, fat and aging activist arts in Canada over the next 7 years. For more information on the Re•Vision Centre see, https://projectrevision.ca/ ; for more information about Rice, see, http://www.carlarice.ca/.

Christine Kelly, PhD is an Assistant Professor in Community Health Sciences at the University of Manitoba. Informed by feminist and disability scholarship, Dr. Kelly uses qualitative methods to explore the politics of care and Canadian disability movements. She presently co-edits a book series for UBC Press, is leading a CIHR Project Scheme study on directly-funded home care, and is involved in initiatives related to disability, aging and care. For more information, see www.christinekelly.ca.

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Endnotes

[1] For other examples of this field-changing work see, Hughes, McKie, Hopkins, & Watson, 2005; Kröger, 2009; Mingus, 2011; Morris, 2001; Murphy, 2015; Robinson, 2006; Simplican, 2015; Williams, 2011.

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Volume 13
Issue 4

Research Article

Too Much or Too Little? Paradoxes of Disability and Care Work in India

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Abstract: The notion of care often normalizes within it violence that can have devastating effects on the lives of disabled people. Cripping care critiques the normalization of such notions of care. This paper articulates this paradox of care within the lived experiences of disabled girls and their mothers as primary carers. Through extensive case studies of young, disabled girls and their carers in villages of West Bengal, Jharkhand, and Odisha in India—where abject poverty, lack of resources, and a dearth of sensitized social relationships remain entrenched—this paper problematizes care relationships, moving beyond social model approaches to include understandings from the Global South of what it might mean to crip care. The paper explores care relationships within the family, which valorize the emotional and physical labor of women in the garb of motherhood while negating the personhood of disabled daughters. While the care relationship between mother and daughter is enhanced by the affective bonds of empathy, emotional responsiveness, and perceptual attentiveness that transform intimate tasks into relationships of trust and demonstrations of trustworthiness, in the unforgiving realities of rural poverty in India the collective act of survival of such families needs to be contextualized within the debates about cripping care.

Keywords: care, disability, feminization

"She cannot do most of the things by herself. Tending to her and caring for her therefore is a big part of my work" (Gautami's mother).

Introduction

Care-giving and receiving raise complex questions and evoke much debate within feminist and disability studies literature. While Tronto (1993) and Sevenhuijsen (1998) have emphasized that care, vulnerability, and mutual dependence are central concerns of human life shared by all, disability studies has problematized care research as objectifying disabled people, who are positioned as dependent and unable to exert choice and/or control and therefore in need of care. Disability studies largely focuses on promoting the empowerment of disabled people and emphasizes the "disabling barriers" of society, including disabling environments and cultures that result in society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization (Oliver, 1990, 2004). Societal barriers are both physical and ideological, and are enshrined within discriminatory and disempowering practices and structures that inhibit the full social participation and citizenship of disabled people (Kroger, 2009). Within disability studies, the understanding of independence focuses on self-sufficiency or the capability of disabled people in terms of choice and control over how necessary help is provided (Morris, 1993). Thus disability studies scholars are critical of care service systems that, through the discourse of medicalization, empower medical professionals to sideline concerns around the right to independent living and availability of services. This reinforces traditional assumptions about people with impairments as needing to be cared for.

On the other hand, feminist ethics of care prioritizes interdependence, relationships, and responsibilities, and understands care as a socially just way of providing personal support for disabled people, one with transformative potential. Kittay (2011) questions the emphasis on independence and choice for disabled people who may find themselves dependent on others for self-care, economic security, and safety. Fine and Glendinning (2005) argue that "to recognize 'interdependence' is not to deny but to acknowledge relations of dependence" (p. 612). While the concept of care values interdependence, it also points to power dynamics within the carer-cared for relationship. Morris (2001) argues that some people's experience of their bodies (their impairments) places them at much greater risk of losing their human (and civil) rights and makes them vulnerable to being denied a good quality of life. Yet the denigration of care and dependency often renders the work and value of the carers invisible, thus creating one oppression in the effort to alleviate another. Kittay (2002) argues that in a care relationship, it is not only the care receiver who is in a vulnerable position; caregivers are vulnerable as well, and at risk of devaluation and domination (Kittay, 1999). The devaluation of care within capitalist and patriarchal social structures increasingly places premium on autonomy, productivity, and individuality over relationality, thereby denying the emotional bond between two people that is closely associated with care work. Thomas (1999, 2004) highlights the fact that social behaviors and power relations that are enacted between "impaired" and "non-impaired" persons, for example in familial relationships, determines the meaning of relationships with others and has an effect on disabled individuals' sense of self, self-esteem, and existential security. The concept of "impairment effects" recognizes that "impairments do have direct and restricting impacts on people's social lives – restricting as judged against socially defined age-norms" (Thomas 2004). Such restrictions are distinguished from the restrictions, exclusions and disadvantages that people with impairments experience as a result of disability (Thomas, 2004). While the primarily western Disability Studies classifies social relationships between those designated impaired and those designated nondisabled, as exclusionary towards the former and privileging the latter, in Asian and other communitarian societies, such notions of individuality, exclusion and accommodation within relationships of care operate through distinctly different norms guided by cultural context, as we will see below.

Recognizing such tensions between the primarily individualist western societies and communitarian global south, we argue that disability studies needs to engage more fully with informal family care because the majority of care is provided informally in families and communities and has invisible costs attached to it, even in societies in which the state provides many services (Daly & Rake, 2003). Going further, we align with both Ghai (2001) and Grech (2009), who argue that the dominance of the British social model in disability studies is unhelpful for the analysis of disability in the Global South. Western individualistic frameworks of care are often inadequate in explaining the ways in which notions of care are subsumed within familial and communitarian ethics in countries like India. Unlike in western contexts, early intervention and rehabilitation are inaccessible to most people. For Grech (2009), who sees impairment as the key issue for disabled people in environments where survival depends on physical labor, the political rhetoric of the social model risks rendering invisible the basic survival needs of disabled people in the Global South. In developing economies of the rural villages in our study, the total absence of care for persons with disabilities within a range of medical, rehabilitation and other institutions means that the responsibility for providing care falls on society, delivered largely within the institution of the family and specifically the mother. Communitarian societies that do not have formal care systems manage dependency collectively in a social context in which the public–private dichotomy is blurred (Chakravarti, 2008).

Alongside Sherry (2007), we call for culturally-specific examinations of disability and impairment. The meaning of disability in the Indian cultural context is embedded in multiple cultural discourses (Ghai, 2001), where notions of dependence and independence, and caring and being cared for are further complicated by impairment. Grech (2013) argues for a move beyond the individual and toward a recognition of different family and community structures while examining the lives of disabled children in the Global South. That is, everyday practices of care need to be contextualized within localized social codes and norms, including shared understandings of caste norms, religious, and cultural practices that shape the everydayness of care practices. The family emerges as the primary site for care, which here includes the management of impairment. In such a context, caring and receiving care becomes a paradoxical experience of enabling/constraint, love/duty, agency/dependence; a situation which is often further complicated by poverty and lack of access to resources.

Further, this paper approaches the care-giving and receiving relationship involving disabled people within families in rural villages in three Indian states with the understanding that care is composed of two indispensable elements: work and emotion (Graham, 1983). Using the framework offered by Thomas (1993, p. 665), which understands care as the unpaid provision of support involving work activities and feeling states, provided mainly, but not exclusively by women to dependent adults and children in domestic spheres, this paper explores the paradoxes of deeply emotional care relationships—dependence/independence, love/duty, paid/voluntary work. Erickson (2005) and Papanek (1979) point out how the twin processes of the valorization and devaluation of care and its association with “natural” feminine tendencies results in what is a curious paradox. This paper situates the care as sets of paradoxes within lived experiences of disabled girls and their mothers as primary carers in a context of abject poverty, a lack of resources and a society insensitive to the social needs of persons with disabilities. Care in such situations implies contradictions, where intimate interdependence signals culturally specific power relationships and constraints alongside prospects and opportunities. Moreover, the overdetermined construction of the mother in

India as the repository of unquestioning devotion and unfathomable care becomes a generative site to interrogate in the case of children with disabilities.

Within disability studies, the role of mothers of children with disabilities has often been pushed into a liminal space because they are often not disabled and yet they can experience forms of disablism (Ryan & Runswick-Cole, 2008). This indicates the need to explore the ways in which mothers of disabled children negotiate, manage and approach their daily lives, operating within culturally-specific mothering ideologies and disabling environments prevalent in the Global South in general, and rural India in particular. This paper examines the paradoxes of care and caring within families and communities with varying levels of training, knowledge and access to rehabilitation services, and therapeutic management of impairments. The dichotomy between the social constructs of care and neglect, for example, must be contextualized as a western creation. Within the complexities of the Indian social context, which involves intersecting strands of poverty, disability, and restrictive gender norms, such straightforward differentiations often do not work. Turning to the lived experiences of those who need help and those who do the work of care shows that caring is complex, and crips normative western assumptions about disability and care in a number of different ways, as we will see.

Cripping care offers a critique of perspectives which normalize violent and/or dehumanizing care regimes. Crip theory is seen to function as a resistance to the norm, and advocates the choice of an impaired individual to call oneself crip and experience pride, instead of hiding or feeling shame. Kafer (2013) argues that studies of disability frequently tone down the individual difficulties of disability, while addressing the very important large-scale issues, such as structural disablism and the built environment; this can mean that pain, loss, and internalised disablism are more often swept under the carpet (Wendell 1996; Hughes & Paterson 1997; Shakespeare 1998). A crip approach, however, may provide a way to include individual issues and bodily problems in a context that addresses both social and personal structures affecting the lives of disabled people.

McRuer (2006) believes that crip is a consciously adopted position, a critical questioning of the norm and how our society privileges the idea of a normative body. Crip theory therefore criticizes the standards that maintain the boundaries of the ‘‘normate’’, which represents the idea of the able-bodied individual. The centrality of the able-bodied individual or what is in fact meant by one, however, is culturally specific. We argue that the idea of cripping needs to be contextualized within the specific settings within which it is applied. In the remote poor villages in which our respondents are located, caring is perceived as oppressive not just for those who receive care but also for the carer. In this context, cripping cannot exist as a binary to oppression, rather, it needs to be understood within and through it, in the limited possibilities in which care becomes a crip relationship. The article seeks to demonstrate that while the conditions of care are often disabling for the young girls as well as their mothers, both are able to crip care within the frame of their relationships and according to their circumstances.

The other point to consider here are the cripping possibilities and their relation to types of disabilities. Sandahl (2003) and McRuer (2006) suggest that the term “crip” includes those with physical, mental and sensory impairments. The questioning of categories in crip theory means that there is no conceptual difference between people with different types of disabilities. Yet McRuer (2006) has focused his work mainly on people with physical disabilities, who are able to express their voice, opinions and dissent clearly, and who dominate the international disability rights movement. On the other hand, there are other groups such as people with intellectual disabilities who do not have the same opportunity to understand what it means to embrace the stigma and to charge the word crip with positive meaning. In the cultural context that this article is located in, such a homogenizing approach to disabilities might be problematic. The specific understandings of ability and disability often provide different possibilities for cripping care.

Therefore Kafer’s (2013:4) “political/relation model” is more useful as it is flexible enough to fit the lives of disabled people, critiquing the power of medicine while acknowledging the need for medical care, and highlighting independent living without denying those who need assistance a voice. This model therefore accommodates the wide variety of needs of persons with intellectual impairments and multiple disabilities and their need for care, especially in terms of how disability is globally located as well as situated differently in particular places and spaces (Wendell 1996; Grech 2012). It is a task of this article therefore to situate the experiences of cripping outside a homogenous understanding emanating from Western experiences and to locate it in a very different cultural context. If cripping is the adoption of a positive disabled identity and representing the voices of the disabled, we ask how do these voices get represented—if the representation is not through oneself as such then does it not count? Also in the culturally specific context of rural poor households of eastern India where our study is located, can we understand cripping as relational made possible through agency shown by the interdependence of people caught within two oppressive structures?

The Context

Our paper is based on fifty-eight qualitative case-studies of young girls with disabilities in poor rural households in eastern India. While it is important to recognize that India is a large and diverse country with significant cultural diversities, some of the observations made in this article will hold true for remote poverty-stricken areas in other parts of the country as well. Participants were identified through organizations working in rural areas within these three states based on criteria laid out for inclusion in the study, which included the economic status of the family, severity of impairment and access to rehabilitation and other support. In order to maintain confidentiality and abide by the standards of ethical research all names mentioned here are pseudonyms. Also the names of the organizations have not been revealed here on similar considerations. Data was collected through intensive fieldwork conducted between October 2015 and March 2016. Fieldwork involved a series of sustained interactions with families, children with disabilities, and primary caregivers using qualitative research techniques like in-depth interviews and participant observation. Research participants include young girls (ages 4-17 years) across a range of physical, mental, and sensory impairments and their families in West Bengal, Jharkhand, and Odisha. Families that participated in this study live primarily in remote rural areas and are poor—they live in one room tenements, sometimes pucca, and with little or no access to toilets. Most of the families have limited access to education and little awareness of their rights or rehabilitation facilities available for their children. The interplay between a child's impairment and the socio-economic conditions of the families and communities in which they live constrains the type and quality of care received by disabled girls in the study. Further, many girls who participated in this study are non-speaking and do not write, and thus rely on their primary caregivers to interpret their communications with others for them. Thus, while centrally recognizing the personhood of disabled girls, this paper focuses on the experience of care primarily from the perspective of and interpretation by mothers. This enables us to understand the dehumanizing nature of care for mothers and their daughters while at the same time locating possibilities for cripping it. The emotions of love, tenderness, and mutual emotional dependence often rescue the process of care from becoming a mechanical set of duties making care relational and multi-layered. We also explore the ethics of care and intersections of gender and class which lie at the core of the lived experiences of disabled girls and their primary carers.

Dividing Care?

In developing countries, the experience of disability and hence the need for care is significantly influenced by access to early interventions for development and rehabilitation. While in the western countries, disability studies has sought to critique and question discourses and institutions of early intervention, we assert that privilege of access to such services enabled the critics to find their voices. The tensions in western framing of binaries of autonomy/ dependence and medical/ social are experienced differently in remote rural contexts of countries like India. While, on the one hand, the cultural connotations of autonomy and dependence are experienced in specific ways in such communities, on the other hand, access to early interventions and rehabilitation is structured not only by provision of services but also by one's social location. Access to early identification and early intervention was limited for most of the girls in our study due to financial and knowledge constraints and lack of access to support services within their local contexts. Everyday material realities also precluded awareness about these possibilities. Kafer (2013) warns against invisibilized the personal experiences of disability through the overemphasis of structural constraints. However, the structural constraints in this case have affected the everyday lives of the girls, with implications for type of care required on a daily basis which in turn determines the cripping of care.

Girls with visual impairments or deafness experienced less functional restrictions, and hence were better able to manage their personal care than more profoundly affected girls with locomotor impairments such as cerebral palsy, as well as those with intellectual impairments and multiple disabilities. These girls required support in almost all physical aspects of everyday life, which means a lot of time and attention needs to be devoted to these care activities. Cripping care has at its core a critique of normative understandings of development, function, severity and of disability itself. While the differences of impairment and the access that the girls could therefore have to life had some variations, in the course of the paper we hope to show that the life experiences of the girls and their carers offered a similar critique, though tentative and often invisible to such homogenizing notions of ability. Disability was one of the many constraints of poverty for these families and thus families focused on adopting strategies that would minimize the need for care as a necessary condition of their socio-economic setup. In such remote locations, mobility or lack of it is not just about the nature of impairment but also its connection with the family's survival. In poor families, this intense level of care is considered a constraint not only in terms of time, but also in terms of the lost labor of those doing care-work, labor that could be used to provide a better quality of life for entire families.

Care is most noticed when it is absent and most appreciated when it can be least reciprocated (Kittay, 2005). Girls with both severe locomotor and mental impairments require full time care and support by their family members for fulfilling their basic daily needs of hygiene, feeding, clothing, and shelter. Tara (age 10) lives with her family in a remote rural village in Jharkhand. As she cannot move about by herself, she sits in one place while her parents, the primary caregivers, feed her, bathe her, and clean her after she uses the toilet). Usha (age 9) has cerebral palsy—she needs assistance in all personal care activities like eating, dressing, using the toilet, and bathing.

In these families, given the need of girls with significant impairments for continuous care, one member of the family is constantly engaged in providing the care required for the disabled child. It is usually the mother who assumes the responsibility for this role. This is almost normalized in rural India where tending to the child forms the core of mothering, a function which increases in significance with a disabled child. In economically poor families, however, this means that there is one less earner, which has consequences for the survival of the entire family (Ghosh & Banerjee, 2016). Arya's mother regrets that her care-giving responsibility severely obstructs her chances to earn money, which in turn could have been used to provide her daughter with better care and support. In contrast, within the task of caring for their disabled daughters, fathers, and siblings seem to play a peripheral role. In many cases the fathers distance themselves from the entire process of tending to their daughters' care needs, thus reinforcing gender stereotypes and cultural taboos. Often, this is connected not only to the father's role as provider within the family but also to status within community. Shrimati's father works in the army and is away from the family for a considerable part of the year from their village in Odisha. He takes no responsibility for her care needs, and shies away when asked. "I am not home all the time, her mother looks after her." However, longer conversations with family members reveal that because he is concerned about his status in the tribal community, he does not want attention drawn to his disabled daughter. In fact, Shrimati's mother has had to discontinue the medicines for Shrimati's (age 16) epilepsy as her father is not interested in procuring them for her from the city where he is posted. Without him providing the medicines it is not possible for the mother both economically and in terms of access (these medicines were not available in the village where they lived) to procure them. This specific instance also illustrates that caring functions are often divided along public-private lines which then map onto gender stereotypes. The public stature of the father and his concealment of his daughter’s disability, prevents him from procuring necessary medicine and compromises the well-being of his daughter.

Among our participants such cases of abject neglect are, however, less common. What is more commonly seen are fathers playing a secondary role in the care of their disabled children. Some of our respondents, such as Shila’s (age 10) mother, said that their husbands do not extend any help in terms of “care”. “Yes, he is very attached to her, he loves her a lot, he buys her whatever she wants and contributes financially, but taking care of Shila is only my responsibility.” In her description of her husband’s role, Shila’s mother makes a separation between “love” and “care”, challenging the dominant Indian cultural norm that care is based only on feelings of love. She specifies that the child is not neglected by the father, who shows an emotional attachment to her, while the physical tending of her daughter remains her responsibility. Thus, the mother classifies care as responsibility and probably even work which is normalized in its gendering.

The supplementary support given by fathers in helping their disabled children further entrench gendered notions of care. In the remote rural setting in which most of our participants live, division of responsibilities meant that fathers usually provided primary economic support which enabled whatever little access to institutionalized form of care, while mothers looked after the physical and emotional well-being of the child. This division of work mapped onto gendered understandings of what care denotes. The role of fathers was seen more as providers of support in terms of seeking rehabilitation and access to assistive devices. Munni’s father fashioned a walker from bamboo for her. Munni (age 16), who has cerebral palsy, can stand upright holding it and also walk a few steps if she so wishes. Lata’s father made a wooden draw-cart suitable for the rural terrain in which they live. Lata (age 15) can sit on it and hold onto the side bar while somebody pulls it by ropes to take her around. Sometimes her friends take her out in this cart to the playground.

The only family in the study where both parents take equal responsibility for the care of their disabled daughter is in urban Kolkata. Mum’s (age 18) father helps her mother provide physical care and mental support to their daughter with cerebral palsy. As Mum’s mother says, “It is imperative that both the parents are able to take care of the child.” Both parents have university degrees and have access to information which facilitated their sharing of caring functions. Even in this case, however, the mother retains the major responsibility for planning and delivering care. This gendered nature of care is aggravated by the local context of poverty, with underdeveloped resources and a lack of physical and financial access to a basic minimum standard of living. The next section demonstrates how care is constrained by these factors in the everyday lives of the families.

Constraints of Care

In poor families especially of rural India where manual labor provides the primary source of livelihood, one of the reasons being born with or acquiring disabilities in childhood is seen as catastrophic is because of the economic implications of caring for the child and managing the impairment. This is exacerbated by a general lack of awareness about possibilities for rehabilitation. One significant barrier for poor families in rural areas is the lack of basic amenities within the home. Many rural areas, such as Jharkhand and Odisha have no toilets. This means additional care responsibilities for the mothers as they have to either carry the child to distant fields used by the village as a toilet or attend to their toilet needs at home. A further complication is the fact that many of the disabled children in the study with severe mental challenges often do not have control nor can they vocalize their toileting needs. Hemanti’s mother cries, “In winter my hands get swollen as I have so much washing to do throughout the day. Now I am getting older I need more time to complete the tasks.”

The onset of puberty adds to mothers’ roles in the physical care of their daughters. The cultural context of rural India comes with a series of taboos and proscriptions around menstruation relating to notions of purity, pollution, and shame (e.g., Bean, 1981). Mothers who have to provide considerable support to their disabled daughters pray for the delayed onset of puberty. In a culture of silence around sex and sexuality within India generally, all girls, including disabled girls and especially those living in rural areas, have minimal knowledge of the reasons behind menstruation. When Munni (age 12), a visually impaired girl started her period for the first time, she thought she had lost urinary control and complained to her mother, who then showed her how to use the sanitary napkins and clean herself during that time. In rural India most women still use cloth as sanitary pads and for disabled girls this is often a necessity not only for financial reasons but also for their particular physical embodiments. For many girls, who can afford only basic quality drawstring panties, thick cotton pads offer better protection during periods, implying less work for the mother. For disabled girls who are able to manage some part of their personal care, mothers teach them like their other daughters, to take care of their menstrual cycles and associated issues. In case of disabled girls who require significant support however, mothers have to provide complete care. Cultural taboos around menstruation in India, which involves avoidance, proscription from certain familial spaces and activities along with a culture of silence, also affect the ability of mothers to seek medical help for disabled daughters when there are problems with the monthly cycle.

Lack of medical facilities and access to treatment creates further pressures on familial care situations. Rukmini (age 18) lives with her family in a remote rural area, so her parents could not access treatment facilities both due to poverty and lack of awareness. As Rukmini has no toilet control, she regularly soiled her clothes and her parents used to come back from work to find her legs full of insect bites. One day when they noticed that ants had gathered on the stool that Rukmini had excreted in the compound, they took her to a doctor who diagnosed that Rukmini has severe juvenile diabetes. This illustrates how seeking professional care is a matter of accident in such contexts. Despite the diagnosis, they have not been able to provide proper treatment for her due to a lack of financial resources. The circumstances of their lives have therefore limited them to prevent harm to her by ensuring that she is not bitten by insects, which will lead to further medical consequences.

Care-giving becomes even more intensive and complex if there are multiple disabled people within a family. Both Khushi (age 9) and her brother have intellectual impairments and have been having epileptic seizures since infancy. While Khushi cannot move about at all, her brother is more mobile, and can perform some of his own self-care. As their mother has to cope with caring for two disabled children along with other household chores, she often asks her impaired son to protect Khushi from the flies and mosquitoes that keep biting her. Rather than infantilizing the disabled child, parents often give them the responsibility to look after the well-being of their profoundly disabled siblings. Similarly, three of Mumtaz’s children have different forms of locomotor disabilities. Since her husband works in another city, she is left with the care and responsibility of all her children. As her teenage daughters are now able to manage their own personal care, Mumtaz can focus all her attention on her son, who is more profoundly disabled. In Mumtaz’s case, the remittance that her husband sends home enables her to access better health care for her children in terms of surgeries, medicines and mobility aids like callipers. In the limited situation of these families, these acts of caring for their siblings undertaken by the disabled children has to be seen as a joint act of cripping by the primary carer—i.e., the mother, the secondary carer and the cared for. The understanding of constraints highlighted in this section is central to understanding cripping care in this cultural context. As argued before, cripping care here is not outside the constraints but is very much shaped by and in turn shapes these constraints.

Labors of Love

As an attitude, caring often denotes a positive, affective bond and investment in another’s well-being. Care, as a virtue, is a disposition manifested in caring behavior (the labor and attitude) in which “a shift takes place from the interest in our life situation to the situation of the other, the one in need of care” (Gastmans, Schotsmans, & Dierckx de Casterle, 1998, p. 53). Relations of affection facilitate care, especially within families. As mothers are assigned the responsibility of caring for their disabled children, the emotional bonds between them become intensified and they develop mutual understanding which may often be invisible to outsiders. Communicating with their non-speaking children with disabilities is one dimension of such intensified relationships and provides illustrations of understanding cripping through a relational lens. Through this communication, daughters are able to exercise some degree of opinion/choice in the process of caring. Arya’s (age 15) mother can differentiate between the sounds of her daughter’s cries. “She makes a particular sound if there is less salt in her food—she does not like it. She also cries if left alone at home.” Rukmini’s mother says while no one else can understand, she can make out when her daughter is smiling as she feels comfortable. This expression of inter-relationship shows that caring is not just a passive process but a relational one which is often fundamentally shaped by the personhood of the daughter. The terms of care in many cases sets the terms for the mother-daughter relationship.

But the responsibilities of care and caring for can, at times, become a constraint for those doing the carework. As girls grow up and become heavier, mothers find it difficult to provide physical care, which often involves lifting grown-up daughters to help with all activities of daily living. Arya (age 15) has to be fed lying down on her mother's lap. Her mother now finds it difficult to fit her on her lap as she has grown both tall and heavy, and it is often a strain to hold her in the lying position. Mothers often carry their children whenever possible even when they move in the neighborhood. Many mothers have stopped going out of the home because their children have become too big to carry around, thereby becoming confined to their own homes and caring roles. Similarly, Aparna (age 16) and her mother, face social isolation as she has become too heavy to be carried around by her elderly father and mother. They are unable to negotiate the two flights of stairs in their home to get out of the house. The care work undertaken by mothers is made more tedious by the lack of supports for both mother and child, and results in mothers forgoing pleasures in their own lives to compensate for other essential structures of support that are missing.

Questions around constraints of care are, however, not straightforward. Notions of sacrifice constructed as a core of good mothering in the gendered cultural framework of India are internalised by many of the women in the study. The patriarchal construction of motherhood as embodying sacrifice and selflessness is valorised. Erickson (2005) illustrates how caring as emotional labor, since it is classified under natural feminine tendencies, is erased under patriarchy. The internalization of gendered performances of mothering, and the privileging of these motherhood ideologies and values, forms the core of the care work of mothers towards their disabled daughters in this study. The "sacrifice", because of its valorization in the shared understanding of the community, cannot be resented within such a framing.

Emotional bonds between those who care and those who need support in this study ensure that the uniqueness of children with intellectual impairments is accepted by their families without protest, even when it affects them adversely. Gauri doesn't sleep until late at night and wakes up very late. Her parents, after tiring daily labor in addition to her care, prefer to go to bed early, but Gauri stays awake. Her mother says, "Once we close our eyes, Gauri starts to pull my hair, poke her father in the eyes and forces us to stay awake till one or two o'clock at night." Yet there are few regrets and a complete acceptance of their child who is unable to mentally comprehend the demands she makes on her parents. While this can be a manifestation of the internalisation of a "natural mothering role", it also needs to be placed in the context of the multiple difficulties that most of these families face. Within harsh conditions of existence, looking after a disabled child is one of the many impediments of daily life. However, the task of caring for a disabled child is one that is taken up with few complaints by the parents and other family members based on ideas of love, duty and familial bonds. What this obscures, often, is that the care provided and received can, through the infantilization and assumed dependency of disabled people, lead to a limiting of possibilities for some disabled children. In the next section we explore this process of over-care and protection.

Care that Constrains

Across the globe, disability is usually equated with infantilism. However in the cultural context of India, this becomes further complicated as notions of dependence and independence are understood and interpreted through identity markers of different status positions that an individual occupies at different stages of their lives. In a communitarian society, where individualist understandings of personhood and independence are subsumed under communal ways of life and determined existence, a crip perspective critiques disabled children as being denied their personhood. Cosseting and overprotection by families, especially mothers, often becomes a barrier to self-growth and progress for these children. Rather than being discriminated against negatively vis-à-vis other children in the household, what is evident in most cases within our study is that disabled children are given special treatment, at times in excess of what is required. This overprotection emerges from viewing caring as mostly a passive, one-way relationship between the giver and receiver of care. Munni is not allowed to do any of her personal care work—her mother brings water and bathes her, takes her to the toilet in the fields and cleans her afterwards, helps her change her clothes and is there for any other demand she may make. Rama's (age 16) mother does not allow her to do any work by herself, fearing that she might hurt herself in the process. This has affected Rama's wish to be involved in her own and her family's work.

The protectiveness of Lata's (age 15) family is evident in the way her family members always insist that she is not able to do things because she cannot walk, "She cries in pain when she tries to stand straight." They acquired a wheelchair for her but emphasize, "It is too high for her to sit so we could not use it at all." The family refused special shoes and callipers for her as they were worried that she would experience pain. Her father says, "How can she walk? How will she hold the crutches?" This kind of over-protectiveness on the part of families, although offered with the best of intentions, often prevents girls with disabilities from achieving different degrees of independence and thus from making the most of opportunities in life. For those who push their children, the results are obvious. Lipika's (age 17) mother revealed that a tricycle was offered to her daughter who has moderate cerebral palsy but she refused it. Lipika's mother felt that, "If she got the tricycle then she would never walk." She ensured her daughter's comfort when she was walking with callipers and crutches. "I tied a cloth at her waist which I held at the back, so that she would not fall."

Over-protectiveness and constant negation of a child's capabilities means that many disabled people remain in need of care and protection throughout their lives in the socio-cultural context of India. When asked, eighteen year-old visually impaired Kokila felt that, if trained, she could make ropes from sabai grass, which is the most common activity in their area. She complains that nobody in her family teaches her to do any kind of work. Her mother immediately responds, "How can she understand only by touching whether the ropes are made properly or not? Can she ever work like any of us?" This denigration of abilities has made Kokila reluctant to assert herself or confidently select her own life-course. The comparative “like us” is a manifestation of the embeddedness of an ableist society’s normative evaluations and reinforces a clear binary between able-bodied and persons with disabilities, of us/them, ability/disability. Similarly, Saloni (age 9) has become so used to her mother and sister catering to her every need that she gets angry if her mother asks her to do any work. Her mother said, “I know it is difficult for her to do the work. One day, in anger over her uncooperative body she asked me to kill her. Since then I never ask her to do anything.” While disability studies has challenged the notion that impaired bodies are helpless bodies, it is evident that the notion of helplessness and dysfunctionality here are the products of the experiences of impairment as equated with infantilization and the negation of possibilities for self-sufficiency and personhood within some familial care situations.

The cultural infantilization of disabled people rendering them unable or unwilling to attend to basic needs accentuates the experiences of disability in their everyday lives, affecting their confidence. As is evident from Kokila’s comments, more than her visual impairment, it is the excessiveness of care that stands in the way of her chances for self-sufficiency. In a curious contradiction, the sense of helplessness around disability is foregrounded through an excess of caregiving.

Crucial Parental Concerns

For girls with profound impairments, parents are concerned not only with providing constant tedious care but also with preventing abuse. More crucial is their concern to ensure that they are able to prevent self-harm. Anupama (age 14) was found missing one evening from her home and after much searching her father found her roaming near a dam one kilometre away. Similar incidents had happened twice before. Her mother explained that Anupama does not do this intentionally; she keeps moving and then cannot remember the way back home. Once, during a monsoon, she fell into the clogged well and was saved only because a local boy heard the sound of her splashing arms in the water and called her father for help. Such life and death situations highlight the limited infrastructure within rural communities.

Security concerns dominate the minds of the families of girls with moderate intellectual impairments because they are vulnerable to sexual abuse both in childhood and adolescence. Karima’s mother found her talking to a stranger who tried to entice her with the promise of food. Out of fear for her child, she started escorting Karima (age 10) to and from school after alerting the school authorities that such a man was preying on female students. Thus, mothers of children with intellectual impairments have to be constantly alert for their children, especially if they are girls, as the threats to their security are great.

Parents worry about the future of their severely disabled daughters. Arya’s mother asks if there is a disability grant available to Arya so that her siblings can be “bribed” into taking care of her. The need to “bribe” her other siblings to take care of their disabled sister contradicts the communitarian understanding of care that has dominated mainstream discourses of care in India. It illustrates how the task of caring is not always naturalised and emotional but requires structures and incentives. Gauri's (age 14) parents hope to find a state sponsored residential facility where she can avail care and protection after their death. Vani's (age 16) story highlights how care is complex, and how structures of care can turn into those of abuse:

> Vani's mother ran away after her father's death, leaving the small girl with severe mental and visual impairment with her aging grandmother. The elderly grandmother works irregularly and spends most of her income on alcohol, as a result of which, they live in destitution. The grandmother loves Vani very much and takes care of her as best as she can, even if it means going hungry herself. Somewhere between her grandmother's absence due to work and her alcoholism, Vani was sexually assaulted twice by an influential man of the village. Villagers say that he gives Vani's grandmother money to buy food for Vani when she is ill, and so no one is ready to protest against him.

Vani's life story as narrated by neighbors and her caseworker, illustrates the complexity of care alongside support, and the many paradoxes that lie at its core, where the family which is projected as a "natural" center of love and care, becomes the space for inadequate care and neglect. Orphaned, and having profound mental disabilities and restricted mobility means that Vani is completely dependent on her elderly grandmother. As the primary caregiver, the grandmother is curtailed by poverty, old age, and drinking habits. The abysmal economic conditions faced by Vani's family force them into a curious relation of dependence with the perpetrator of abuse, thus making him a stakeholder in Vani's care. The complex nature of the structures through which care is delivered becomes entangled in the relationship with the perpetrator of sexual abuse. The carer therefore cannot always be clearly distinguished from the abuser. It is often the very structure of abuse that functions as the structure of care, complicating the binary between carer and abuser. While Vani's case is a particularly stark example of this, the ways in which care is provided within other families also hides a patronizing, dehumanizing, and humiliating notion of disability. It also raises the question of how girls like Vani can crip care? As McRuer (2006) argues, the possibilities for cripping care are immense for persons with disabilities but raise the crucial question whether girls like Vani can understand how to charge the word "crip" with positive aspects. In such cases can we consider the work that her case-worker and destitute grandmother does with her to be efforts of cripping? The more obvious illustrations of cripping care in the next section makes this contrast an important concern for advocates of crip theory.

Cripping Care

Within these limiting notions of care there are, too, narratives of hope. After two of their children were born blind, and one died at the age of three years, Munni's parents decided to stop having children and concentrate on Munni's upbringing. This was not about physical tending, but instead about acknowledging Munni as a human being with life chances. As Munni's mother said, "I want her to study and learn so that she can help herself. Some of our relatives said, 'She cannot do anything, she doesn't have a future.' My husband and I decided we will put in all our efforts to raise Munni so that she can take care of us." She further elaborates, "I want her to be self-dependent and lead a respectful life, that's why I constantly push her to be more self-reliant. Yes, she has a disability but she has to be a strong person."

In a context where the entire core of society is premised on ableist terms, disability—especially in poorer households—spells insurmountable difficulties for children as well as their parents. Advice of willful neglect of such children is commonplace. In such settings, the very act of living and strategizing by children and their primary carers constitutes resistance. In this scenario, Munni and her parents challenge a dehumanizing notion of care. Munni and her parents— even if in limited ways through their decisions—critique the normate in a society where everything is premised on ableist terms. The focus on self-reliance, respect and strength as a person, crips the notion of care. By foregrounding transgressive possibilities and a collective agency, the family views care as relational.

Mum's mother recounts that she gets into arguments with her daughter regarding everyday choices of clothes, food, etc., not just for Mum but for herself as well. Once again, this mother-daughter relationship illustrates a cripping of care practices. In this case, care is relational as there is recognition of the individuality of the disabled daughter, who may be dependent for all her individual needs on her parents, but is still able to voice her choices, which are respected. These few instances illustrate how care becomes more than a one-way exchange structured by poverty and cultural constraints, and instead is conceptualized as exchanges in which those who perform the care work and those who receive support are mutually constituted through learning and exchange. This establishes the care relationship as symbiotic and reciprocal (though not necessarily symmetrical).

Conclusion

Disability studies has powerfully illustrated how the notion of caring for people with disabilities has justified abuse in various forms. Our research, which draws from feminist political economy and ethics of care, however illustrates that there is no unilinear trajectory for understanding care relationships. The responsibility of caring for disabled children within disabling contexts can be limiting for both the receiver and the giver of care, and can work to reify care roles in ways that elide how disability might also crip care, as the previous section illustrates. Within disabling contexts of care, care work is feminized labor that increases the workload of the primary carer, and can also signify a deficit of agency on the part of the disabled recipients.

Care as a form of feminized, naturalized labor operating through patriarchal logics masks the exploitation inherent within it. It is further constrained by equating care of disabled children as a passive relationship. The notion of cripping care allows us to explore the two-sided exploitation within a patriarchal, neo-liberal (state withdrawal from services automatically limits the marginalizeds' access to service) notion of care. While the illustrations of care in this paper might suggest the existence of a power hierarchy between the primary carer and cared for (i.e. the mother and the disabled daughter), the reality is far more complex. Studies in the West have shown that those thrust into the unexpected “career of caregiver” for a child with a disability (Boaz & Muller, 1992; Hoyert & Seltzer, 1992; Keith, 1995; Pruchno, Patrick, & Burant, 1997) experience stressful life situations that can have negative consequences if health care and social service systems are inadequate. Becoming an informal caregiver is not typically chosen or planned; people do not envision being in a caregiver role when they project themselves into the future. The role is taken up by them through the naturalization of familial ethics of care without any additional training or resources available to them. In the context of the remote rural areas of the study, becoming an informal caregiver manifests itself in conceiving of care in terms of physical tending to the disabled girls rather than in focusing on their autonomy to make care choices. To conceive and perform care as a process in which the autonomy and personhood of the disabled girl is developed through a reciprocal process is a more time-consuming process.

This process also requires a sophisticated understanding of individuality and disability which is neither available nor applicable in the cultural context of poor households of rural India. In the situation of rural poor India—constraints with limited resources and limited understanding of possibilities in the lives of the disabled children—it becomes easier for mothers to limit care-giving to a performance of physical tending akin to other household tasks. This severely curtails possibilities available to their disabled daughters.

Moreover, an informal caregiver lacks rights, privileges and prerogatives that come with a formal career status. Caregiving duties, in most cases, are subsumed under natural mothering responsibilities and rendered invisible as housework. The role also differs from occupational careers as it is driven not by personal ambition, but rather by the progression of the impairment and the functional dependencies it creates. Finally, a caregiving career cannot be entered into and left at will, especially by women, who shoulder the major burden of caregiving responsibilities in the home. It is therefore our contention that this patriarchal notion of care actually marginalizes both the actors while further embedding this dominant care ethic.

Our stories demonstrate the urgency with which such families require not just financial and medical support from the state but also psychological support services. This is all the more acute in a context where the neoliberal state is rapidly withdrawing from care and the erstwhile familial structure disintegrating due to increasing nuclearisation and urbanisation. The vulnerabilities of these families become even more pronounced with their marginal social position and harsh realities of their impairments.

At the same time, the constraints of these experiences do not disqualify the possibility of agency. Herein lies the cripping of care. In a context where life-chances are conceived in ableist terms, disabilities spell dual marginalities for the girl and her family. In the unforgiving realities of rural poverty in India, the collective act of survival of such families becomes a tale of resistance against all odds, a pushing back against stereotypes of disability. The lack of facilities, sensitization and access to resources probably preclude a more radical take towards the lived realities of these disabled girls, but in the absence of such grand acts of resistance, the everyday survival of these girls and their mothers show us that resistance can take such invisible forms too. Proponents of cripping care have spoken of the transformative potential of the notion of cripping. In the context of the constraints that we were researching in, it is not useful to map cripping through transformations, big social changes or qualitative improvements. This, however, did not necessarily mean that there was no transformative potential in these acts. Cripping care in these contexts was made possible through everyday acts of survival.

Further, these largely passive notions of care are complicated by relations of affect. While an unpracticed eye might not be able to map the agency of the girls in this “cared for” relationship, the ties of intimacy between the mother and daughter often enables the latter to communicate her needs, wants, likes, and dislikes to the mother, and assert their importance. By seeking to frame her care within these preferences, she no longer remains a passive recipient of the care process. While talking of this as autonomy might be an exaggeration, she is able to exert her opinion in many cases. This can be seen as being akin to forming alliance which has agential values. Williams (2001) notes that often care is rejected in favor of alternative concepts such as empowerment (particularly where it emphasises choice and control) and support. She feels that while the ethics of care emphasises interdependence and the relational, disability activists using the social model of disability have argued for the strategic centrality of independence, autonomy, and control over one’s life. But in this case, there is an important distinction between conceptualizations of autonomy as self-sufficiency, and autonomy/independence as the capacity to have choice and control over one’s life (Williams, 2001). This alludes to feminist care ethics (Petterson, 2011) which perceives care as a relation of intimacy. While we are aware of the oppressive equations of disability and dependence which can be masked within this ethics, we contend that a true feminist care ethic has at its core mutual dependence and reciprocity.

An examination of the questions of care and caring within the lived experiences of the families and communities in this study illustrates how the process of care is multilayered and paradoxical and cannot be understood by situating it within binaries. Both the carer and receiver express agency through strategies that they use singularly and/or together to manage their impairments and disabling circumstances. The care relationship between two people is enhanced by the affective bonds of empathy, emotional responsiveness, and perceptual attentiveness that transform unpleasant intimate tasks into times of trust and demonstrations of trustworthiness, gratifying and dignifying to both those who provide care and those who receive care.

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REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL
Volume 13
Issue 4

Research Article

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

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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 Erevelles, who have both moved the conversation surrounding care and mental disability forward in highly generative ways. Erevelles 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" (Erevelles, 2011a, p. 38). Erevelles, 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. Erevelles 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" (Erevelles, 2011a, p. 38). Price builds on the materialist work of Erevelles 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 (Erevelles, 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 “needscapes.” Needscapes 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, needscapes 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 Irigary. The authors utilize Irigary’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 phallocentric 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 Torrant's contention that “affective needs can be realized if and only if basic needs are met” (p. 195).

I agree with Torrent’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 responsibilization 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 responsibilization 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 (Rodriguez, 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.

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REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL
Volume 13
Issue 4

Research Article

What Is a Service Animal? A Careful Rethinking

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Abstract: I argue that the discursive tactics used to maintain a clear boundary between "legitimate" and "illegitimate" service animals rely on a set of assumptions that perpetuate unequal relations of power, and ultimately harm others (human and nonhuman alike). In support of this argument, I outline my theory of crip spacetime, which draws upon the material feminist notion that disability is an intersectional and emergent phenomenon, becoming (rather than being) through intra-active environments. Thinking through the ontology of service animals and their human companions in terms of crip spacetime demands that we apply what Christine Kelly (2016) has called accessible care in relationships.[1]

Keywords: service animal; ethics of care; spacetime

> I am returning home from the 2016 National Women's Studies Association (NWSA) conference in Montreal, Canada. I arrive at the Columbus International Airport, where my partner Johnna will pick me up in a few minutes. Ordinarily I would take a car service home from the airport, but this evening I am utterly undone, in tears, hardly able to find my way out of the building. I texted Johnna in the middle of the night, telling hir what happened, and now ze is on hir way to meet me.[1]
>
> As I step through the outer doors by the baggage claim, into the smell of car exhaust and cigarette smoke, I see a sign on the wall through which I've just passed:

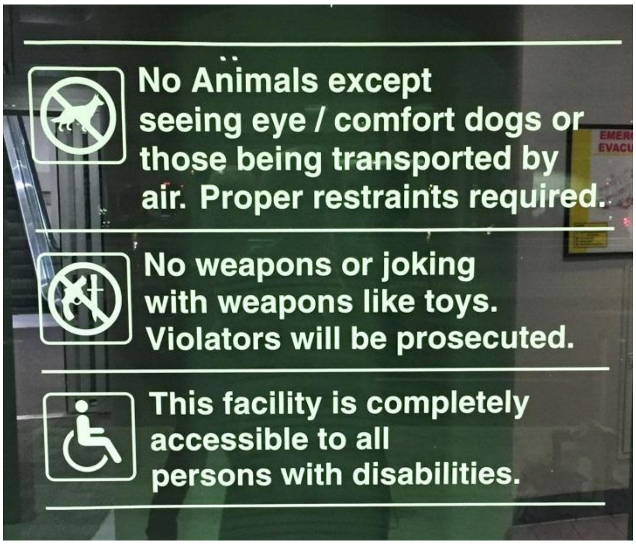

Image description: A greenish-white stenciled sign on a glass wall. It comprises three sections, arranged vertically. The first section, accompanied by a stencil of a medium-sized dog with a circle around it and a slash through the circle, reads, "No Animals except seeing eye / comfort dogs or those being transported by air. Proper restraints required." The second section also has a graphic, this time of a handgun and a knife being crossed out by a circle and a hash mark. The text in the second section reads, "No weapons or joking with weapons like toys. Violators will be prosecuted." The third section's graphic is an upright stick figure in profile in a wheelchair, accompanied by text reading, "This facility is

> completely accessible to all persons with disabilities."

I offer this sign as a starting point to explore a question that's been on my mind for many years: What is a service animal? I started asking the question because I was personally concerned about my own service dog, Ivy—which means I was also concerned about myself. But as I continued to ponder Ivy's and my ways of moving in the world, I realized there are larger questions to consider. These include the meanings of "service" and "care"; what it means to make care into a site of labor performed by animals; what it means when we combine animals' capacities and disabilities with our own; and what all that might teach us about the intersecting qualities of animal, human, and world. In this essay, I explore these questions through a theory I call "crip spacetime." Described in more detail below, crip spacetime draws upon both structural and new materialism to explain the ways that disability "becomes" through space, time, objects, texts, and organisms. Particularly, crip spacetime can be discerned in the tensions, affinities, and violences between and among those—for example, as a wheelchair becomes both a gendered person and a body part (see Belser, 2016), or as the mineral lead becomes racialized (see Chen, 2012).

My overall argument is that the discursive tactics used to maintain a boundary between "real" and "fake" service animals rely on a set of assumptions that perpetuate unequal relations of power, and ultimately harm others (human and nonhuman alike). However, this project carries risk, because any attempt to re-define "service animal" has the potential to place people and animals at risk of harm in other ways. I take seriously what it means to question this definition. Handlers' lives, not to mention livelihoods, often depend on their service animals. The appearance of poorly behaved animals who are claimed as service animals does harm to other teams, who are already subject to constant comments, harassment, and discrimination (see Siler). Thus, the stakes are high, and I am rethinking with care.

No Animals

A different, but more common, starting point could be the legal discourse that surrounds and constitutes service animals. According to the Americans with Disabilities Act (ADA), a service animal is a dog or miniature horse "individually trained to do work or perform tasks for a person with a disability."[2] Service dogs and service miniature horses can enter restaurants, stores, schools, and public buildings; fly on airplanes and ride buses; live in housing where pets are not allowed; and so forth. Legal restrictions are few. If the animal "compromises legitimate safety requirements that are necessary for safe operation" (e.g. is too heavy for a small plane) he may be legally turned away.[3] Also, if she isn't housebroken or well controlled by the handler, she can legally be refused entrance to a public space such as a restaurant. U.S. law specifically forbids asking about service animals if their functions are "readily apparent." Even if the function is not readily apparent, questions are strictly limited, and in most cases, no documentation or proof of certification is required.

Looking outward from legal definitions, it's well documented that animals have been providing service to humans for thousands of years.[4] Rebecca J. Huss (2010) notes that "dogs were kept at healing temples in ancient Greece," and that pictures of dogs leading blind people have been found in thirteenth-century Chinese scrolls (pp. 1166-1167). This history is repeated in many articles about service animals, sometimes with additional details about early examples of animals being specifically trained to assist disabled people (Wenthold & Savage, 2007), and gaining more detailed focus in the period following World War I, when dogs were first trained to serve as "seeing eyes" for blind veterans (Eustis, 1927; Eames & Eames, 2001). As the twentieth century progressed, the forms of care deemed "service" proliferated. Animals had been formally trained to work with deaf and Deaf people at least by the 1970s, and shortly thereafter were documented as providing service for "depression, panic disorder and post-traumatic stress disorder" (Huss, 2010, p. 1169; see also Eames & Eames, 2001). With the 1990 passage of the Americans with Disabilities Act (ADA), and its subsequent amendment in 2010, the legal definition of "service animal" in the U.S. was codified. However, as a flood of reports from scholarly, personal, and popular news sources show, the interpretation and enactment of this definition have been anything but simple.

I mentioned that I have a service dog, Ivy. She's about nine years old. She also weighs five pounds, cannot walk fast due to patellar luxation, and is almost completely blind. When she accompanies me to work, on errands, to doctor's appointments, or on trips, she rides in a carrier that hangs by my right hip. Details of her breeding and puppyhood are unknown. I do know that she lived the first part of her life in traumatic circumstances (mostly neglected, sharing a house with 27 other dogs), after which she was rescued by an organization in north Georgia. I adopted her in 2010.

The details in the previous paragraph may have already disqualified me as a legitimate handler of a legitimate service dog in some readers' opinions. It's often assumed that "service" by an animal requires substantial size and strength. Popular accounts about fake service dogs often seem to get in digs about the suspicious nature of small size, as in this 2009 article quoting a grocery-store worker: "Like when you see little Foo Foo in someone's purse, you know that's not a service animal" (Yardley, 2009). The crudeness of this attitude is not shared by most advocacy and/or training organizations, though, which are well aware that service animals come in many sizes, and that their human companions' disabilities may not be immediately apparent. For example, *Anything Pawsable*, a news and information magazine for the service-animal community[5], features an item titled "How Can I Tell if a Service Dog is Legitimate?" which argues that the most accurate way to identify a service animal is not through size or breed, but through behavior (n.d.). However, *Anything Pawsable* also includes dozens of items aimed at drawing a sharp distinction between "legitimate" and "illegitimate" service animals; in fact, the category "Fake Service Dogs" occupies its own page on the site, along with "Gear and Equipment" and "Training Tutorials." The reasons for maintaining such a sharp distinction, according to *Anything Pawsable*, are many: for instance, fake service animals may hurt or frighten members of the public because of a lack of training, which "casts a shadow on the entire [service animal] community"; they may distract legitimate service animals from doing their jobs; and they may undermine the seriousness of a service animal's purpose in the first place ("The Hidden Complications").

In other words, even though *Anything Pawsable* recognizes that service animals and their human companions are extremely diverse, it still emphasizes the importance of maintaining a boundary between the real and the fake. That same policing impulse—to draw sharp lines between "real" and "fake," "legitimate" and "illegitimate"—is shared by many service animal breeders, trainers, and handlers.[6] This process is what Ellen Samuels (2014) would call *biocertification*—that is, constantly looping bureaucratic processes which take as their goal "the determination of the 'truth' of disabled bodies" (p. 123). As Samuels emphasizes, these looping processes are never about disability in isolation, but always caught up with other often-policed categories, including race, gender, and citizenship. Correspondingly, the tactics used to maintain the boundaries around "service animal" draw from many intersectional discourses. In the next section, I explore a number of those discursive moves, which invoke topics as broad-ranging as health, safety, fitness, obedience, excellence, measurement, and dirt. These disparate topics all call forth a similar public anxiety about *bodies out of place*: bodies that don't look the way they are supposed to, function according to standards of "excellence," excrete in ways considered "dirty" rather than properly contained, and so forth. My purpose is to question the governance of animal as well as human bodies, and especially the governance of animal-human relations.

Proper Restraints Required

> I carry a piece of paper everywhere I go: a letter signed by my psychiatrist. The letter specifies the tasks Ivy performs, and that I have been diagnosed with "more than one serious mental illness listed in the Diagnostic and Statistical Manual of Mental Disorders 5." It also lists the nature of the limitations on major life activities that my disabilities cause, and describes how Ivy's tasks mitigate those limitations.
>
> I rarely mention this letter, even if Ivy and I are challenged as we enter some space. Usually, I'd prefer to take a minute to educate the questioner, both for my own and for other service-animal companions' sakes. But if the negotiation becomes lengthy or if I'm particularly debilitated that day, I may say something like, "I can show you a letter from my doctor," which almost always resolves the conversation in my favor. For some reason the mere invocation of the letter serves as its own evidence.

Crip spacetime as a theory attempts to map the world in terms of the knowledges that disabled people have been communicating—to each other, and increasingly, to others—for quite some time now. It is not intended as a model, but I do offer it as a corrective to some of the concerns about the social model that have led over the past 10-15 years to crip theory, cripistemology, and critical disability studies. These concerns often point to a series of overly simple divides posited by various versions of the social model, including person/environment and impairment/disability, as well as the attempt to collapse all disabled bodies into a single (implicitly white, male, cisgender) figure. In response, crip spacetime turns its focus away from the human individual to focus on the spatial, the relational, the non-human animal or object, and the group. In crip spacetime, there is no clear distinction between "person" and "environment"; rather, disabled life (and death) become through a complex dance of space, time, objects, texts, and organisms. In this way, the theory of crip spacetime draws upon Karen Barad's (2007) new-materialist theory of intra-activity. However, crip spacetime also draws upon the more structural-materialist point of view of writers like Nirmala Erevelles (2011, 2014), who insists that the violences of inequality—for instance, racial and global inequalities—must be not only "recognized" but must be at the center of what we understand as the becoming process (pp. 28-29). I am not calling for a both/and move, but rather, drawing upon Christine Kelly (2016), for an ongoing and hopefully useful *ambivalence* between these two approaches.

Thinking through situations in terms of crip spacetime demands that we apply what Kelly (2016) has called "accessible care" in relationships. This form of care recognizes that intimate relationships are always emerging in the context of larger systems of power and violence; that we cannot choose sides among independence, dependence, and interdependence, but rather must constantly navigate the tension among these concepts; and that we must be willing to dwell with a certain amount of ambivalence. Kelly argues, "Ambivalence provides breathing room by allowing some of the seemingly irresolvable debates to simply remain irresolvable" (p. 40). Accordingly, crip spacetime refuses the desire to purify disability into a nugget of information—e.g., "My disability is *this*, so access (or service, or care) will look like *that*." Rather, crip spacetime asks us to question notions of consistency, individuality, functionality, and coherence when they are applied as evaluative tests for who and what should be valued, and in what ways. Moreover, it demands a focus on both the particulars of intra-active situations as they unfold, as well as the systems that produce and justify unequal, violent relations based on human exceptionalism (Taylor, 2017; see also Ferguson, 2013). In the following sections, I apply crip spacetime to a specific example, my own service dog, by analyzing the discourses that seek to define "real" service animals—as well as other discourses, which resist those boundaries by seeking a more capacious way of recognizing service and care from/with animals.

Ivy would be instantly ruled out as a potential service animal by most breeders and trainers. Trainer Kea Grace's (2016a) article "10 Things That Make a Dog Unsuitable for Service Dog Work" names "structural imbalances" and "vision or hearing problems" as two of the dealbreakers; Ivy has both. Grace also lists a range of issues Ivy does not have, but which similarly resonate with disability and fitness[7]: "genetic illness," being "overweight or obese," and "timidity." The emphasis on health continues in another article by the same author (Grace 2016b): not only should a service animal be housetrained, but any illness causing gastric upset should be "very, very, very, very rare." (This sentence made me pause and wonder about illness that might cause only "very, very" or "very, very, very" rare occasions of upset.) The importance of near-flawless health and behavior is repeated over and over again, not only in *Anything Pawsable*, but in myriad other publications dedicated to explaining what service animals are and are not. Assistance Dogs International (ADI), for instance, puts it this way:

> Assistance dogs have to work to the highest possible standards of health, welfare and task work. The standards are a critical guide for all ADI member programs and are vital in defining what an assistance dog is.

With the phrase "what an assistance dog is," ADI ties excellent behavior and health to the very definition of service animal. If a dog is badly behaved or unsound, it's not just a bad service animal—it's not a service animal at all.

To be clear, I'm not saying service animals *should* be incontinent, riddled with anxiety, or disruptive. Rather, I'm trying to unearth the assumptions surrounding service animals—assumptions about health and fitness, of genetics and breeding, and of contamination and safety (including frequent discussion of excrement). These themes reflect the arrangements of life and matter identified by Mel Chen (2012) as "animacies": a hierarchichal ordering based upon "understandings of lifeliness, sentience, agency, ability and mobility in a richly textured world" (29). Following Chen, I'm interested in how this ordering works, and also how it is tied to other orderings having to do with consistency, productivity, and safety. If we considered the possibility of a service animal-human relationship that was more mobile, even more fragmented—less coherent—than its conventional form, what new possibilities might emerge for ways to think about disability (and human animals, and animals)?

Thinking in terms of crip spacetime means recognizing the possibility that a five-pound, bow-legged, blind rescue dog could be fully *fit* to participate in a relationship of care that qualifies as "real" service. But it also means recognizing that such an investigation may do harm as well as good. The presence of service animals in public space is usually fraught, and there are good reasons to uphold an image of service animals as near-perfect organisms. Companions of service animals are constantly challenged, questioned, and discriminated against; meanwhile, the animals themselves are subjected to uninvited greetings and touching. Emily K. Michael (2016) tells of moving through the world with her service dog York, routinely deflecting people "digging for medical details or distracting York with high-pitched puppy talk." Sometimes, such encounters turn violent, as in Stephen Kuusisto's (2016) "Denied a Cab Ride, Grieving for Who We Are." In this essay, Kuusisto details the "contempt and mean-spirited bullying" he experienced when trying to arrange a cab ride from Detroit to Ann Arbor. The story has many painful turns, including this one, which occurs just after Kuusisto mentions that he writes for the New York *Times*:

> He [the cab driver] began shouting that Donald Trump had won the presidency and "you people" (apparently meaning blind New York *Times* readers) "don't matter anymore." He was absolutely vicious and crowing about how people like me don't matter.

Elsewhere in the same piece, Kuusisto describes the driver as “sneering” and “abusive.” And his story is not an anomaly. Advocacy sites and message boards within the service-animal community offer thousands of other examples. Moreover, harassment may be the least of a companion’s problems: her life, not to mention her livelihood, may depend upon her service animal remaining undistracted and unthreatened. Little surprise, then, that disabled people are sometimes among the fiercest defenders of a clear line between “real” and “fake,” “fit” and “unfit” service animals.

And yet it is also disabled companions of service animals—including Kuusisto (1998; forthcoming) and Michael (2016)—who write about this relationship with the most subtlety and the deepest attunement to “becoming” in company. Rod Michalko (1999) calls the relationship “The Two-in-One”:

> At one time, I am master; at another, [guide dog] Smokie is. Now I am handler, now he is. … This is a fluid relation that does not apply when leader and follower are understood as static and completely separable entities. Thus mastery, handling, and ownership are situated phenomena and not ontological ones. … We move together as one, touching and imagining both each other and our world. (p. 185)

The relation Michalko describes is strikingly like the intersectional process of “becoming” discussed by Erevelles (2011, 2014). Note that Michalko describes himself and Smokie as “imagining both each other and our world.” Moreover, though it was published almost 20 years ago, Michalko’s description of himself and Smokie as bringing one another *and the world* into being resembles Barad’s (2007) theory of intra-activity. Pre-existing human and pre-existing animal do not come together in a pre-existing environment; rather, the relation constitutes human, animal, and the matter of the world.

But becoming is not a neutral process (Erevelles, 2011, 2014). It unfolds through and because of unequal, often violent, histories. For animals, those histories include subjugation, torture, and neglect, as well as (in the case of dogs) a long entanglement with humans through which the two species became mutually reliant (see Taylor, 2017). For humans, those histories include colonial violence, ableism, and racism, as Erevelles explains, as well as a struggle to figure out how we understand ourselves, other animals, and objects as members of what Kelly Oliver (2016) calls “the moral community” (p. 248; see also Ferguson, 2013).

I have been wondering “What is a service animal?” (and “What is service?” and “What is care?”) because these questions demand that I also ask what it means to be (or rather, become) a disabled human in the world. Oliver (2016) points out that attempts to police boundaries between humans and animals through criteria such as functionality or sentience lead to “the nonproductive type of line-drawing” that inevitably seems to end in declaring a hierarchy of ways to exist (p. 253). I want to take up Oliver’s suggestion that we understand people and animals through a version of feminist care that emphasizes “an ethics of proximity” (p. 242; see also Ferguson, 2004). This form of care might move beyond an individualistic model of "service"—one animal, one human—to consider more complicated forms of collective care. But it would also consider the material costs of doing so.

Comfort

> Mid-November 2016. The NWSA conference-goers, thousands of us, arrive in Montreal reeling from Donald Trump's election just a few days before. We invoke it in our presentations, we tell stories about how we learned the news, we organize resistances, we cry. We hold onto each other longer than usual when we meet and when we say goodbye. Many of us avoid the windowless session rooms with their rows of front-facing chairs, sitting instead in small groups, talking, touching each other. We seek comfort.
>
> Ivy is not with me, for complicated reasons. I hesitated over the decision. I had to weigh it against the stress that the trip would have placed upon both of us—particularly since it involved crossing an international border—and I ended up deciding to leave her home. (One of the ironic things about being accompanied by an animal whose job is to ameliorate panic is that the constant questioning and periodic harassment that flare up in her presence may actually bring on panic.) Only after I arrive at NWSA, when my friends express sorrow at Ivy's absence, do I realize that she could have comforted them as well.

The term "comfort animal" is archaic, but still crops up with surprising regularity—for instance, stenciled on the glass wall of the Columbus, Ohio airport. It vibrates with notes of domesticity and home culture ("comfort food"); of violent transnational and sexual histories ("comfort women"); of animals themselves ("creature comforts"). If the term didn't make me so *un*comfortable, I might even claim it, since comforting is one of Ivy's most important jobs.

But comfort is not supposed to be a service animal's job—or "task," as it is defined by U.S. law. A service animal, according to C.F.R. § 36.202, must "do work or perform tasks" for a person with "a physical, sensory, psychiatric, intellectual, or other mental disability." Comfort is, in fact, explicitly outlawed, according to Title III:

> The crime deterrent effects of an animal's presence and the provision of emotional support, well-being, comfort, or companionship do not constitute work or tasks for the purposes of this definition.

This emphasis on "work or tasks" is frequently used to govern the difference between "legitimate" and "illegitimate" service animals. Joan Esnayra, founder of the Psychiatric Service Dog Society, notes that ADA lawsuits may be won or lost on the word "task": "If you say 'comfort,' 'need,' or 'emotional support,' you're out the door," she is quoted as saying in a 2009 New York *Times* article. "If you talk about what your animal does in terms of 'tasks' and 'work,' then you stand a chance" (Skloot, 2009).

The distinction between service animals and emotional support animals (ESAs) is similarly defined in terms of work or tasks, and comprises a curious web of overlaps and differences. While service animals may enter more spaces, they must be dogs or miniature horses; by contrast, an ESA may be any species. The variety of species permissible as ESAs has led to a number of sensationalized news stories reporting on claims made on behalf of ferrets, iguanas, ducks, pot-bellied pigs, monkeys, cats, goats, boa constrictors, kangaroos, and parrots. Patricia Marx (2014) wrote a first-person account that describes obtaining a letter from a "therapist type" and then entering various public spaces with (one at a time) a turtle, a snake, a turkey, an alpaca, and a pig. Marx's piece is written for comic effect, but her tone is often dismissive, if not sneering. For example, she notes that the National Service Animal Registry recorded 11,000 emotional-support animals in 2013, then asks, "What about the mental well-being of everyone else?"

Although pieces like Marx's are meant to be taken lightly, their appearance signals a growing sense that the proliferation of many different kinds of ESAs (including reptiles and rodents), combined with legal confusion over which kind of animal qualifies for what, may be undermining and endangering people with "legitimate" service animals (Kogan et al., 2016; Skloot, 2009; Teitell, 2013). As a result, organizations that advocate for service animals and their companions have doubled down on their exacting definitions of "task," "work," and "support," in an effort to debunk widespread charges of fakery. For example, *Please Don't Pet Me*, an advocacy site founded and maintained by service-animal handlers, offers a dedicated article on "Understanding the Differences Between Tasks and Work," while *Anything Pawsable* offers a full article to distinguish between "tasks" and "natural behavior."

Attempts to define "task" often link this concept to another one: trainability. *Anything Pawsable* quotes trainer Susan Lilly Grace: "Any behavior offered by the dog that isn't directly trained and linked to a cue is considered a natural behavior" (McCormack, 2015). Thus, if a disabled person begins to shake from anxiety, and her dog jumps on her lap in a comforting way through his own initiative—but *not* because he was trained to do so on that specific cue—that is a "natural behavior," not a "task." This trainer also mentions that "companionship" and "emotional support" don't count as tasks, because they cannot "easily be verified on a specific cue."

That argument isn't hard to agree with if the task in question is something that can be physically observed, such as jumping on a person's lap. However, if we think about less easily observable behaviors, where does "task" end and "natural behavior" begin? For example, let's return to Susan Lilly Grace's point about the "natural" behavior of a dog trying to comfort his human companion. What if the comfort required is not periodic (and thus cue-able), but constant? I clicker-trained Ivy, and I know that in order to cue a dog, you need at least two things (besides the clicker): you need an occasion on which the dog is doing the behavior (the "task"), and you need an occasion on which the dog is *not* doing it. As the trainer, you must click at the very instant the behavior occurs. Your dog learns that hearing a "click" means *Right! Yes, that! That thing you did at that exact moment!* So if I click for Ivy just as her hindquarters touch the floor on a sit, the sound tells her *Hindquarters on floor=you met the goal*. According to clicker-training methods, a reward should follow the clicking, so that your animal remains invested in the training. But the click itself is not the reward; rather, it's a signal of *when* the rewardable behavior occurred, and an assurance that a reward will be forthcoming at some point.[8]

But at what point does providing support or comfort *become* a task? The desire not to engage this question leads to murky, sometimes rather tortuous, use of language. For example, the ADA National Network explains that ESAs "sometimes help with depression, anxiety, and certain phobias, but do not have special training to perform tasks that assist people with disabilities." (As a trainer, it is tempting to imagine perverse versions of cue-able "tasks" that would transform this "help" into "service"—for example, if an animal does silly tricks on cue, thus making the depressed or anxious person laugh and feel better, is she now a service animal?) The ADA National Network document attempts to clarify the "task/support" distinction by explaining that a psychiatric service animal's tasks might include "reminding the handler to take medicine, providing safety checks or room searches, or turning on lights for persons with Post Traumatic Stress Disorder, interrupting self-mutilation by persons with dissociative identity disorders, and keeping disoriented individuals from danger." Some of these are easily recognizable as individual tasks that can be trained and cued; others, such as "keeping from danger" might be more difficult to pick out. As someone who is routinely disoriented with brain fog and cognitive delays, I can testify that one of the most disorienting features of disorientation is that you often don't realize you're disoriented, or to what extent. Ivy certainly helps keep me from danger in such situations, but not usually because I've given her a specific cue.

Tasks performed by psychiatric service animals seem to present particular difficulty to those attempting to interpret the "thicket" of laws and regulations surrounding service animals (Lipka, 2011). An article aimed at helping university counselors form policy, for example, explains that a psychiatric service animal might "prevent" compulsive or destructive behavior (Kogan et al., 2016). Is "preventing" something a task, if that task must be cue-able? It's not hard to see that one could make an argument for "preventing" in terms of observable, identifiable moments—e.g. pulling someone's hand from their mouth if they're biting their fingers, or preventing them from stepping into a busy street if dazed. But it also seems evident that "keeping from," "preventing" (as well as "soothing" or "calming") might not be easily identifiable, and cues might not be easily demonstrable. Or, to put it another way—at what point does "help[ing] with depression" become "preventing self-harm or suicide"? If the presence of an animal causes self-harm or suicide not to begin in the first place, where is the *task*?

Perhaps in an effort to de-emphasize the complicated "task/natural behavior" division, many advocacy sites suggest that service animals' realness is related to the length of the training process. For example, *Please Don't Pet Me* notes that "Service dogs receive hundreds of hours of socialization, advanced obedience training and formal training to perform the jobs for which they were intended." No matter how well-trained a pet might be, this article explains, it almost certainly has not been through those hundreds (or thousands) of hours of learning how to work. But a certain amount of slippage persists, unremarked, in that argument. For example, what if the human companion's needs are not so complicated, and training could be briefer? Does that mean the needs themselves are less urgent, the disability itself less severe? Do all human companions need to be disabled in ways that require *excellence* from our animals? The argument for excellence is compelling, since it is tied to the more general public attitude toward service animals and companions (who, as noted earlier, often experience discrimination and harassment). Many publications, including *Please Don't Pet Me*, remind the reader that inappropriate behavior on the part of a service animal creates a "ripple effect" that has negative consequences for all service-animal teams.

And yet, I want to ask—are those really the terms on which we want to defend ourselves, going forward? Is unswerving excellence (except on "very, very, very, very rare" occasions (Grace, 2016b)) an acceptable price for being allowed to travel, go to school or work, receive medical care, and participate in cultural events? Is that how we want to pursue the argument about our own value as disabled people? For that matter, has it ever worked for any oppressed group to try to maintain perfection as the price of admission? It makes sense to me that one should not visit a restaurant accompanied by a dog who habitually craps on the floor.[9] But is it crucial that the animal be flawless, or nearly so? There seems to be an alarmingly eugenic discourse at work, through which the hardworking, genetically optimal, perfectly behaved service animal is held up as a standard for all disabled people and their animal companions.

The current system of defining service animals assumes that humans have clearly recognizable disabilities, which open up specific needs, which in turn can be met by the work of a service animal (its tasks). But if we think about the complex, caring relationship between service animals and their human companions in terms of crip spacetime, the bright lines between human-disability-need-animal-task dissolve. In fact, every service-animal companion I've consulted with in the writing of this article acknowledges a subtler, more nuanced relation between themselves and their animals than legal or even public definitions would allow. The lived experience, as my friends and acquaintances describe it, makes room for ambivalence. Insistence on clear lines between "real/fake" or "natural behavior/task" tends to arise in response to the external violence of discrimination that is the daily experience of most service animals' companions. In other words, most people with service animals whom I know personally tend to regard the relationship as intra-active: emergent, fluid, a becoming-together. But they also recognize the violence that is part of that becoming.

No Weapons

> I stand on the sidewalk outside the Columbus airport, breathing the damp, chilly air filled with car exhaust. I am almost nonfunctional. That's why I noticed the sign in the first place: I am moving slowly, not processing anything aural, and staring

at things I wouldn’t ordinarily notice, like the lines between the squares of linoleum on the floor, or signs painted on glass walls.

I am in this state—drifting and dull, post-panic-attack—because the person in the seat behind me on the plane was drunk and violent. He spent the flight rocking in his seat, occasionally punching my seat, and saying “Fucking cunt” about the flight attendant when she refused to serve him any more alcohol. The flight attendant departed the back of the plane for a safer area, while the man continued to swear and occasionally punch my seat. I froze, lost my breath, and didn’t move or turn around. After the plane landed, I waited until he was gone. Then I asked the flight attendant if I could file a complaint.

I won’t detail the process of attempting to make that complaint. I talked to the gate agents, then their red-jacketed supervisor, then (fifteen minutes later) the police officer they said had to be called because the airline (Delta) couldn’t do anything. By the time the police officer arrived, the drunk man had left the gate, the flight attendant had climbed back onto the plane and flown away, and the officer laughed at me and said, “Well, what do you want me to do about it?” I looked at his badge and he said, “You can look at my badge number all you want, it won’t do you any good.” Then I decompensated and was unable to speak for a while. I remember the officer asking (not kindly), “You want me to call you an ambulance?”, to which I shook my head and walked away. I remember leaning against a wall and texting Johnna to come pick me up. I remember that I couldn’t see very well, but I found the escalators and the moving sidewalk that led me to the baggage claim. I stepped on the pad in front of the automatic doors, moved outside into the fume-filled air, turned back to look at the glass wall, and saw the sign.

Johnna arrives with both our dogs in the car. Maybe I wouldn’t have decompensated if Ivy had been with me, or maybe I still would have. Maybe the officer would have taken me more seriously if I’d had a marked service animal by my side—or maybe less so. Maybe the presence of a small dog would have made the drunk man less violent, or maybe more so. I don’t know. I do know this: When Johnna arrives with the dogs, I am not in need of my service animal specifically. I just need anyone—preferably everyone—in my family.

On the sign whose image I showed at the beginning of this article, discourses of violence (“No weapons or joking with weapons like objects. Violators will be prosecuted”) are tucked between the top statement (“No Animals”) and the abruptly utopian turn of the bottom statement (“This facility is completely accessible to all persons with disabilities”). Interestingly, only the middle statement—with its images of a gun and a knife, and its unsubtle reminder that even “joking” about weapons is grounds for detainment—mentions actual prosecution. Although the top statement also warns against illegal activity, it does not mention any consequences. In fact, the *subject* of those first two sentences is entirely absent, from a grammatical point of view. But in the statement about weapons, potential lawbreakers are named: they/we are “Violators.” Paraleptic non-mentions of race, nationality, violence, and policing appear between the lines of this sign as “shadows”—affective elements present but unnamed (Adams & Erevelles, 2015).

Those same shadows hang over all animals in U.S. airports, including the pets and ESAs and service animals waiting with their companions in the security line; the police dogs moving quietly beside their handlers; and the thousands of human animals thronging the halls and trying to get somewhere else. Some shadows are cast from hundreds of years ago, some from the present day: dogs used as weapons and tools of surveillance; Lynndie England holding a leash while dragging a man by the neck in Abu Ghraib prison; the comparisons made between Michael Vick’s appearance and that of a pit bull (Weaver, 2015). All human-animal relations are shadowed by the cultural process Barad calls “thingification” (2003, p. 812). For example, as Sunaura Taylor (2017) documents, European and American sideshows of the 19th and 20th centuries featured acts such as Ape Girl and Jo-Jo the Dog-Faced Boy, which “played out the various colonial and scientific dramas of their time.” In these shows, Taylor recounts, “animality was front and center—with the most demeaning of animal comparisons being reserved for people of color and for intellectually disabled people” (p. 104). The medical-scientific logics used in the becoming of race and disability were also logics that transformed people into animals, and animals into objects, and objects into despised, unworthy matter. Indigenous and feminist versions of object-oriented ontology both point out and resist these violent processes, while simultaneously emphasizing the importance of recognizing agency in nonhuman actors (see Kristen Arola, 2017; Kim TallBear, 2011). If one is attuned to these histories, it is eerie to note the implications in the words of Dorothy Harrison Eustis’s *Saturday Evening Post* article from 1927: “The dog must have perfect obedience and yet he cannot be a machine.”

Animals and objects cannot ethically be used as stand-ins for that which we wish to posit as less-than. Rather, we must acknowledge humans, animals, and objects as differently valuable entities (Gibson, 2006; Haraway, 1991, 2008; Kafer, 2013; Kim, 2015, 2016). In some cases, we may observe that objects have animal-like or human-like qualities; in others, that we ourselves are animal-like and object-like, *without* allowing that observation to signal “a necessarily degraded status that licenses violence” (Kim, 2016, p. 141. See also Belser, 2016; Taylor, 2017). My call to crip care in the service animal-human relationship is fueled by more than a general sense that it’s the right thing to do. It is also fueled by my conviction that if we do not work our way toward a more capacious, more fully relational understanding of what a service animal is (and thus, what we ourselves are), we will continue to perpetuate the violences that accompany the hierarchization of animacies (Chen, 2012). We will literally be saying that some animals are more equal than others.

Is there room to recognize, both theoretically and materially, that perhaps we could move away from the assumptions of unswerving excellence, cleanliness, and hyper-ability that characterize most legal and institutional definitions of “service animal”? Can we take up the possibilities, and also the costs, of a less controlled proliferation? I am inspired by Emily

K. Michael's investigation into the many encounters she manages every day as she moves through the world with York. Michael points out that, although people's endless questions can get tiresome, they also reveal "patterns of thinking about the more-than-human world." She notes that many people comment sadly that they miss their own dogs, and rather than taking this as an opportunity to emphasize the difference between the carefully-trained York and others' (presumably) not-as-thoroughly trained dogs, Michael takes a different turn. She asks: What if humans *did* have animals accompanying us more routinely into public spaces? How might our spaces change, and how might humans' relations to one another and to animals change as well?[10]

At the close of her book *Beasts of Burden*, Sunaura Taylor (2017) states that that for several years she had a service dog, Bailey, who then became disabled because of spinal surgery. Now, she writes, "[My husband] David and I are undoubtedly Bailey's service humans" (p. 223). And yet, Taylor points to this relationship not as the end of Bailey's work as her service animal, but as an extension of it:

> There is a sense of something appropriate—beautiful actually—about being a gimped-up, dependent, inefficient, incapable human supporting and being supported by my inefficient, dependent, and gimped-up dog. … Awkwardly and imperfectly, we care for each other. (p. 223)

Taylor would be the last person to suggest that this awkward, imperfect relationship should be taken as a generic ideal. Bailey might not, of course, be the right "fit" for a different disabled person. But Taylor's relationship with Bailey fits her, fits him, fits their world, and is a form of care that should be valued—in legal and institutional as well as personal ways. There is room for many kinds of service animals in the world. Acknowledging this means not only recognizing a different kind of care in human-animal relations, but caring about those relationships differently as well.

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Endnotes

1. My thanks to the human companions who have helped me develop and revise this piece: Kennan Ferguson, Emily Michael, Rod Michalko, Bethany Stevens, Sunaura Taylor, Tanya Titchkosky, and Melanie Yergeau. Thanks also to Ryan Sheehan for his extensive research support, and to the reviewers and editors who have made this piece so much better. Any remaining errors of fact or judgment are mine.
2. Laws governing service animals in the U.S. include C.F.R. § 36.202; the Americans with Disabilities Act (ADA), including its 2010 amendment; the Fair Housing Amendments Act (FHAA); and the Air Carrier Access Act (ACAA). The Department of Transportation's *Guidance Concerning Service Animals in Air Transportation* (2003) is also often cited. Laws outside the U.S. vary; Assistance Dogs International (ADI) and the International Association of Assistance Dog Partners provide information about international law.
3. When referring to unspecified service animals in the singular, I use the pronouns "he" and "she" by turns.
4. Unless otherwise specified, "animal" in this article refers to "nonhuman animal."
5. Eames & Eames (2001) document the emergence of a subculture of disabled people who are partnered with service animals, particularly dogs.
6. In addition to the potential harms to animals/handlers noted earlier, the appearance of animals in public space may harm those who are debilitated by phobias, allergies, or other problems that make it difficult or impossible to be around some kinds of animals. In exploring what it might mean to crip the definition of service animal, I do not mean to argue that its potential problems are unimportant. Harm and pain are important, and should receive more attention in new-materialist theories.
7. By "fitness," I mean a metaphorical fitting/misfitting, as defined by Rosemarie Garland-Thomson (2011): a "material arrangement" through which a body/object is more or less congruent with the surrounding, and shifting, circumstances (p. 594).
8. This description is a very brief overview of one positive-reinforcement training approach. My thanks to Sharon Wachsler and Caroline (CMoore) Moore, who introduced me to this method, helped me find books and resources on the subject, and offered feedback on my training videos.
9. Since I'm in the habit of thinking about limit cases, even this example doesn't seem so terribly extreme when I consider the fact that I am routinely expected to swim in public pools that babies and children have both urinated and defecated in, to touch doorknobs and elevator buttons teeming with fresh bacteria, and to shake hands with people who have recently been sneezing, coughing, wiping their faces, and picking their teeth. In general, human bacteria and environmental toxins are a greater threat to me than a dog taking a shit in my vicinity. For more on the complications of dirt, contagion, and toxicity in public space, see Mel Chen (2012, 2014) and D Adams and Nirmala Erevelles (2015).
10. As noted above, an abundance of animals in public space would not be an unqualified good. People with phobias or allergies, for example, might be harmed. My point is not that we should create a sort of hipster utopia, with dogs sitting on barstools beside their human companions (as much as that image might charm me personally). Rather, I want us to re-think the ways animals are allowed to be part of our systems of care, particularly when those systems insist on rigid definitions of *disability* and *need*.

REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL
Volume 13
Issue 4

Research Article

Teaching and Care: Cripping Fieldwork in Teacher Education

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Abstract: Providing teacher candidates early and ongoing opportunities to learn their profession by participating in school settings is often posed as a way to improve their preparedness for becoming teachers. Two problems of "fieldwork," however, are the limited access to settings in which inclusive education is practiced and the milieu of special education in the US that emphasizes ableist assertions of independence, support, and conventional notions of care, especially for youth characterized as intellectually disabled. We present an overview of the establishment of a "cripped" fieldwork experience for early program teacher candidates enrolled in a required undergraduate course. By engaging in qualitative narrative analysis of candidates' journals, we report preliminary findings on evolving notions of care related to disability and education in self-reported field-based learning.

Keywords: teacher education, care, field experience, field-based learning, disability

Providing teacher candidates early and ongoing opportunities to learn their profession by participating in school settings is widely recognized as a way to improve their preparedness for becoming teachers. Two problems of "fieldwork" however, are the limited access to settings in which inclusive education is practiced and the milieu of special education in the US that produces ableist assertions about learning and independence. Such assertions constrain educational opportunities offered, especially, to youth characterized as intellectually disabled (Cowley & Bacon, 2013; Kliewer, Biklen & Kasa-Hendrickson, 2006; Wehmeyer, 2006). Taub, White, and Ryndak (2014) report the need for development of inclusive education and point out, "when students with complex instructional needs are in general education contexts to learn the same content as their grade-level classmates, [they] experience membership derived from participation in shared activities and can demonstrate progress in the general curriculum" (p. 272). Despite efforts to improve inclusive education, high quality models of practice are rare (Smith, 2010). Fieldwork, in which a teaching intern is placed with an "expert" teacher to observe and become acclimated to the field of practice, is more likely to acculturate new teachers into practices and norms that reinforce ableism and exclusion. Delport and Daikos (2015) suggest that teacher preparation programs look outside of traditional fieldwork in schools to provide candidates with experiences that can lead to new understandings and innovative ideas about youth, families, and communities, rather than learning to reproduce problematic practices embedded in many schools. It is with this idea that we (co-authors) founded the Increasing Access to College (IAC) project.

The IAC was initially formed as a partnership with Growth Program, a day habilitation center for adults with intellectual and developmental disabilities, to develop a college-based experience to be mutually beneficial for Growth clients and university-based teacher candidates. Growth program leaders saw the IAC as a novel opportunity for their clients to experience a college environment. We envisioned the project as one with the potential to co-construct space at the university through which Growth participants might be enabled to envision, perform, and be imagined in their possibilities as college learners. At a time when postsecondary programs for students with intellectual disabilities are proliferating, the intent of the IAC is to provide an initial opportunity to explore university life for students who are rarely recruited or groomed for college admission. Growth IAC participants described opportunities to learn about college life, engage in challenging academic experiences, and interact with college students as highlights of the program. Two clients expressed interest in entering credit-earning programs in the future, while others did not; many participants elected to return to the IAC for continued engagement as part of Growth or other partner programs, and others were satisfied with a one-year experience.

As Growth participants gain from accessing the campus, the IAC also provides a reciprocal benefit of being able to “crip” fieldwork for teacher candidates, which is our primary focus in this paper. “Cripping,” explains Sandahl (2003), “Spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects” (p. 37). Our aims in the IAC, then, were to create a context in which partnerships between teacher candidates and Growth participants could be formed as reciprocal learning experiences. In emphasizing engagement with participants as the primary space in which learning could emerge—rather than in internship with teachers or staff—we sought to position Growth clients as agentive. We aimed to set a stage in which teacher candidates could develop dispositions toward reciprocal, instead of authoritative, relationships with people with disabilities.

We are engaged in ongoing exploratory qualitative research on the IAC project for the purpose of program evaluation and development, as well as for scholarly inquiry. Areas of interest in the broader study include participant-reported gains and benefits of the IAC, collaboratively generated perspectives of participant and community stakeholders on desired aims and outcomes for postsecondary education, and the impact of IAC activity on the campus community. Each of these areas inform how the IAC may pursue continued program development with close attention to stakeholders’ interests. This article focuses on the impact of the IAC on teacher candidates, in which a theme of care emerged through our analysis of their journals of self-reported field-based learning. An opportunity to examine the connection of care to relationships and reciprocity as dispositions for teaching unfolded.

Care and Education

Care is a contentious topic in feminist and disability scholarship. Critiques of the labor and conditions of care workers (Duffy, 2005) and lively dialog on interpretations of care ethics are present (Diller, 1988; Hoagland, 1990). Scholars in disability studies critique the ways in which people who use support are positioned in paternalistic relationships of care, limiting their claim to personhood and right to direct the manner of support (Hughes, McKie, Hopkins & Watson, 2005; Kelly, 2013; Morris, 2001). Literature that addresses care and teaching students with disabilities demonstrates a variety of ways that care is conceptualized in educational practice. At its broadest level, care means building and nurturing relationships among teachers and students that are rooted in love, empathy, and desire for community (Lepage, Nielsen & Fearn, 2008; Hong et al., 2009). Care is also conceptualized as the educator's desire to advocate for individual students and families or make political change to improve educational equity (Freytag, 2008; Lepage et al., 2008; Woolhouse, 2015). A third way that care is described is as a focus on students' "progress and happiness" (Humphrey, cited in Woolhouse, 2015, p. 138), which means attending to individuals' accomplishments and desires in order to aid in transforming children's views of themselves (Hong et al.; 2009; Lepage et al., 2008). Marks (2011), in contrast, finds that others' frequent associations of "patience" and "caring" as a primary attribute of special education teachers diminishes the professional and intellectual labor of educators of students with the most complex support needs. While many suggest that a disposition of care is important to teaching, some perceptions of care, especially for teachers of students with disabilities, can be problematic.

Ethics of Care in K-12 Education

Nel Noddings is a frequently referenced theorist who proposes the ethics of care to guide reform in school and curriculum practice (2005a; 2012). Noddings' (2005a) intent is to offer the concept of care as an alternative orientation to the competitive cultures in many schools. Noddings' ethics of care suggests interconnectedness, as it may be nurtured through reciprocal relationships, enables children to grow as individuals and in accordance with their individuality. Essential to Noddings' notion of care is the difference between the virtue of care—caring about something or someone—and engaging in a caring relationship, in which caring is offered and acknowledged in acts of reciprocity. Caring requires that recipients perceive and interpret actions as caring. Caring interactions, Noddings (2005a) describes, emerge through having a consciousness that enables engrossed listening, in which one can "really hear, see, or feel what the other tries to convey" (p. 15-16). Motivational displacement enables us to leave our own purposes and thoughts aside in order to shift thought and action toward furthering another person's aims or desires. Caring is not a trait or a presumed motivation, but is performed in acts of careful listening and interconnected understanding and action.

Beginning with Gilligan's (1982) germinal work in feminist ethics, ethics of care and its place in moral philosophy have been debated and refined over several decades. Central concerns relate to a lack of critical feminist consciousness in Noddings' discussions and lack of universality of both the ontology of the mothering relationship on which an ethic of care is modeled and the impossibility or undesirability for the model to work in varied domains of human experience (Diller, 1988; Hoagland, 1990). In other words, there are questions about whether the specific relationship and context for care experienced between a mothering figure and child can be extended to human relations without such origin and intimacy. The intimacy and interaction required by this construction of care can perhaps relate to interpersonal relationships, but is less feasible as an ethical principle that expands beyond those with whom we are not imminently engaged. Held (2006), Tronto (1993), and Slote (2007), as just some examples, provide additional conceptualizations of ethics of care that respond to some of these concerns.

We do not forward Noddings's ethic of care as a universal ethical framework, nor do we address the concept as may be imagined for comprehensive school reform. Like others who have applied her work to situations of K-12 teacher practices, we seek to understand how care between teachers and students may be described by reciprocity, engrossment, and motivational displacement. Care and caring are concepts that seem to inform the identities and perceptions made of teachers and the profession of teaching in ways that warrant examination of its meaning in practice (Marks, 2011; Woolhouse, 2015).

Care and Education for Students with Disabilities

Care in education is complex when considering disability and the history of segregated special education practice. The education of students deemed disabled in intellect, emotion or social capacity has been influenced by views of caregiving and beneficence that are constructed with assumptions of incompetence in academic capability (Bredberg & Davidson, 1999; Kliewer, Biklen & Kasa-Hendrickson, 2006; Wehmeyer, 2006). The result has been "a different and separate education for these students," that is "based on custodial care and teaching self-care skills rather than providing a truly meaningful education" (Marks, 2011, p. 80). Such approaches, Marks (2011) suggests, characterize the labor of educators as "charity work," rather than work aiming to ensure that "individuals are provided with equity and opportunities to be fully integrated members in our communities" (p. 80). Ayres et al. (2011), in contrast, state the presumption that less reliance on care—or independence—is most desirable to improve quality of life. They argue that the most appropriate education for students with severe disabilities should be focused on functional and vocational skills to enable independence.

Rather than solely emphasize independence, Hughes, McKie, Hopkins, and Watson (2005) and Kröger (2009) draw from disability studies to point out that care, support, and assistance need to include choice and control of supports within a value for interdependence. Different from the view of curriculum described by Ayres et al. (2011), we propose that being enabled to participate in activities one chooses enhances quality of life. Choice in how disabled children and adults direct assistance or select to pursue any given educational, social, or recreational interest may be approached in resistance to the ideal of "compulsory able-bodiedness" (McRuer, 2006) that is accentuated in the practice of special education. Educational opportunities are constrained or withheld for young disabled people when they are directed within an ableist construction of independence and support. Ethics of care instead emphasize interconnectedness and interdependence as a basis for human relations.

In critique of care scholarship that fails to address the perspectives of people with disabilities using support, Morris (2001) asserts:

> "Whatever 'care' is—whether it is in the form of formal services, cash payments, or personal relationships—if it does not enable people 'to state an opinion,'

> ‘to participate in decisions which affect their lives,’ and ‘to share fully in the social life of their community,’ then it will be unethical…We need an ethics of care which recognizes that anyone—whatever their level of communication or cognitive impairment—can express preferences” (p. 15).

A meaningful shift in educational practice, then, is to challenge assumptions that idealize independence and limit choices. Offering students with disabilities the range of opportunities and experiences afforded to other students is essential for education intended to lead toward satisfying adult lives. Support systems created through a value for interdependence may be created for engagement in expansive opportunities, which may then be targeted and pursued in accordance with students’ goals and expressed desires (rather than in others’ assumptions about their futures). Ethics of care provide a useful, even if tentative, framework to honor and value the interdependence of all lives, which counters the venerated notion of independence that drives and constrains school experiences for students deemed intellectually disabled. Noddings brings attention to ways in which school practitioners may strive to create reciprocal caring relationships, rather than beneficent notions of care, more commonly assumed about special educators (Bredberg & Davidson, 1999).

Cripping Care for Teacher Education

Care in education occurs within relationships of reciprocity that enable teachers and students to direct their energies in concert. We disagree that care is “an interaction between adults and students, whereby the adult does what is best for the welfare of the student,” as Mihalas et al. (2009) describe. Neither is reciprocity in care “giving in” to what every student wants (Hong et al, 2009). “Care ethics,” Noddings (2012) writes, “emphasizes the difference between assumed needs and expressed needs. From this perspective, it is important not to confuse what the cared-for wants with that which we think [they] should want” (p. 773). Simultaneously, Noddings (2005b) acknowledges that there is usually some level of inference in striving to understand another’s expressed need. Yet, engaging through an ethics of care is characterized by engrossment in attending to what is expressed by the other, rather than inferred by oneself. Reciprocity involves the desire and inclination of both/all parties to understand and acknowledge what has been expressed, provided, and/or received, even if fulfilling the need or want is not possible. Care is a relationship between students and teachers to be developed through and for empathy, advocacy, and the shared journey toward students’ self-actualization. An ethic of care suggests that we nurture relationships not as a means or strategy to ease negotiations of needs, wants, and responses, but as a way of relating and honoring shared humanity and desire to support each other’s pursuits and inclinations.

Assumptions about incompetence in decision-making and fear about presumed vulnerability of students with disabilities are barriers to reciprocal relationships (Cowley & Bacon, 2013). The performance of self-direction and self-actualization of students with intellectual disabilities, Cowley and Bacon (2013) point out, is shaped and narrowed by emphasis on a view of independence that is informed by dominant values associated with compulsory able-bodiedness (McRuer, 2006). First, disabled students are only offered opportunities that seem possible for them to do independently as the basis on which to form aims and desires for adult life. Second, "self-determination" in schools is promoted as a set of special education skills to be performed by disabled students and then judged as "appropriate" by educators, service-providers, or caregivers. A cripped view of care is instructive in this area. Rather than rely on a notion of independence as aiming to reduce care needs, a value for interdependence expands the imagination of what may constitute education that enables satisfying life experiences. Caring relationships between students and educators enable moments in which individual desires may then be understood and pursued to direct learning toward self-actualization (Gunn, 2012). A proposition for teacher education is to explore ways that teacher candidates can prepare and practice being attuned to learners in ways that resist assumptions and presumptions that have informed educational practice for disabled students.

Study Design: Cripping Fieldwork for Teacher Candidates

Over the past two years we have collected a range of exploratory data on the IAC project for the purposes of program evaluation and research related to inclusive postsecondary education and teacher education. Data sources include field video, transcribed planning and advisory meetings, field notes, informal group, and individual interviews collected during participant observation, artifacts capturing participant accounts of their experiences and learning, and reflection journals of teacher candidates. This article focuses on written journals that capture learning and impressions of fieldwork as self-reported by twelve teacher candidates during a 15-week university-based course.

Participants

In 2016, 31 early-program, undergraduate teacher candidates enrolled in a required course for their dual-certification program in subject-area and teaching students with disabilities.

The Growth program, a local day habilitation center, arranged for 20 participants and 4 support staff to attend the public university located in a metropolitan area in the Northeastern USA one afternoon per week. Participants from Growth attended the university in consistent groups of 10 participants and 2 staff, each group on a different day (e.g., A-day; B-day). Twelve teacher candidates were split into groups of five and seven, according to their availability, to team up with groups of ten participants from Growth. The field experience took place weekly for 12 weeks. "A-day" candidates consisted of three women and two men; "B-day" candidates were six women and 1 man. The twelve teacher candidates ranged in age from 20-23; and include one who identifies as Black, all others as White; one self-identifies as having a disability. Teacher candidates in the dual degree program must possess a 3.25 (of 4.0) grade point average for admission, which is one indicator of the high educational achievement of the group overall. All 20 Growth fellows meet eligibility for state Division of Developmental Disabilities services (2008), which indicates their status as people with "severe, chronic" disabilities that result in "substantial functional limitations" in three or more areas of major activities of daily living. Nearly all Growth fellows received K-12 education in segregated special education programs and schools. They range in age from 22-33; eight are women; twelve are men; three are identified as having Latino heritage; two as Black or African-American; and the rest Caucasian. All participants elected to attend the IAC program from a selection of several other community-based activities offered by Growth. Participation in research was voluntary and conducted with approval of the University's Institutional Review Board.

Methodology and Data Source

The class aims to introduce philosophy of inclusive education. Prior to fieldwork, teacher candidates completed three 2.5 hour class sessions that provided readings and discussion related to medical and social perspectives on disability (e.g. Baglieri & Shapiro, 2012), person-centered planning (e.g. O'Brien & O'Brien, 2000) and examples of college programs designed for students with intellectual disabilities (e.g. Hart, Grigal & Weir, 2010). Care was not a stated theme of course instruction. Explicit instructions included expectations to work in partnership with fellows as peers, not "staff" or "teacher;" to get acquainted with each other to find connections and shared interests; and to participate together in on-campus activities that they sought out. Teacher candidates were encouraged to approach the experience as if they were showing the campus to a friend or prospective student and making plans based on what their guest wanted to do or learn about as they consider the demands and opportunities offered by college.

Graded assignments for teachers included creating a weekly journal, for which options in format were offered, and engaging in a person-centered planning experience, which culminated in a partnered poster presentation of Growth participants' thoughts and goals related to college. For reflection journals most teachers submitted typed, continuous prose, though some included photos, offered hand-written journals, or used bulleted points to express ideas. A few used online blog services to host their journals. Regardless of form, all weekly journal entries were expected to include a) description of what the group did that week; b) discussion of the teachers' impressions of the day and learning related to subsequent planning; and c) critical analysis, which meant a discussion of how the week's experience related to course themes of disability and inclusive education. The journal data set consisted of approximately 89,000 words in 353 pages created by the twelve different teachers who agreed—one month after the end of the course—to enable the use of their journals for research purposes.

Data Analysis

As an exploratory study, the research aims are open-ended and are intended to describe and understand the experiences of all involved in the IAC. Established areas of analysis include attention to participant satisfaction and learning—referring to university-based students and IAC participants (all of whom are titled "IAC fellows" in daily operation), partner program staff, participant family members, and campus staff. We are also examining characteristics of the types of campus experiences that appeared and felt inclusive, exclusive, authentic, and/or staged. The instructor of the course redacted all names and identifying information in order to provide an electronic data set with masked identities for other researchers to analyze. One researcher who was not the course instructor completed a first round of coding for journal data using an iterative process of narrative analysis to develop categories to organize themes emerging through immersion in the narrative data (Miles & Huberman, 1994).

Our primary emphasis in this article is on the content presented by participants and the ways they seem to employ concepts of care to describe their experiences. An interpretivist approach to analyzing meaning acknowledges that understandings brought forth in research are partial and shaped by gendered, raced, abled, and classed discourses that shape human relationships in the broad cultural context of the study. Individual experiences and positionalities within patriarchy, white supremacy and nativism, disablism, and social hierarchy also influence the specific worldviews of researchers and participants.

Limitations

The analysis presented in this report should be treated as preliminary analysis of one facet of a broader study. Teacher education literature often recommends that teacher candidates and novice teachers write journals to capture or provoke reflection to enable development of practice (Bain, Ballantyne, Packer & Mills, 1999; Coulson & Harvey, 2013; Davis, 2006; Ulusoy, 2016). Journaling in the context of a graded assignment in a graded, required course demands consideration of teacher candidates' authenticity, especially in relation to their explicit discussion of course themes, as required by the assignment. Caring, it may be noted, was not one of these themes. In other words, care emerged in several teachers' journals, but was not a concept assigned in readings or as a course theme on which they were required or even specifically encouraged to discuss. We accept that performance of ideas in journals remains meaningful as an expression of learning; we propose that journal-writing can both capture learning and provoke reflection to enable learning (Vanhulle, Vite, Balslev & Dobrowolska, 2016), although we recognize that questions of authenticity may be raised. Future analysis of the fuller data set for the study will enable testing of themes in corroboration with video data and the impressions of other study participants, notably IAC participants and partner program staff. Continued efforts to establish inter-rater reliability in future rounds of coding will also add to confidence in the findings presented in this report.

Findings

In this article, we present examples of self-reported learning about care that the teacher candidates described in their journals. We highlight selected exemplars from some journals to illustrate themes that appeared in varied students' writing. The themes are: (a) a benevolent or charitable approach to teaching (Marks, 2011); (b) questioning meanings of care; and (c) teacher candidate descriptions of care-related learning.

Entry Points: Hopes Towards Care-Giving

The first journal entry for all teacher candidates was written before beginning fieldwork and captures their hopes, questions, and fears. Some imagined care as something that they would give to fellows, as exemplified by Marisa:

> “Our class seems to be composed of compassionate and capable future teachers who truly care about students with disabilities…I know that I definitely want to do a good job because I’m a caring person who wants to make a difference through my teaching…I won’t give up until I feel that I’ve created a good experience for my students.”

In this example, the perception of care relates to duty and is presumed in the work of making a difference for another person. Marisa communicates a somewhat distanced approach to caring, irrespective of individuality and instead focuses on “students with disabilities” more generally. Another teacher candidate, Emma, explains, “I was nervous but excited. I knew this would be the first stop in a long journey to achieve my mission: This was the first chance I would get to have a positive impact on someone's life.” At the start of the experience, Marisa and Emma seem to imagine the aims of fieldwork as a one-directional enactment or impact of care. Care is something that fellows might perceive and receive, and that teacher candidates express as part of a sense of mission.

Ava similarly describes her intentions for the project, but does so by explaining a goal that is more mutual and interdependent. Ava states, “One of my goals for this fieldwork experience is to really connect with the fellows. I hope by the end of the semester, the fellows and I will share a bond from the time we have spent together. I hope the fellows will learn that I care about them and want the best for their time at MSU.” Ava, like Marisa and Emma, expresses a desire to give care to the fellows, but unlike other teacher candidates, Ava describes that she hopes to share and connect with fellows, indicating a desire for mutuality beyond a one-sided expression of care. At the outset, then, teacher candidates express ideas of care as both benevolent and mission-driven, as well as hint toward imagining alternative caring relationships that are reciprocal in nature.

Reflecting on Experiences: Questioning Meanings of Care

Progressing through the weeks, many teacher candidate’s reflections became focused on the significance of particular interactions. A detailed entry from Marisa’s journal offers an example of how she used a particular situation—a critical incident, perhaps—to raise questions about how care may be enacted and received. We break the journal entry into parts interspersed with commentary on Marisa’s contemplations of care. The scene begins with a description of two Growth program staff members’ interaction with a Growth fellow, Jaiden:

> “The two [program staff] with us were talking casually with one another, and reminding themselves how they always had to be prepared for everything and anything. [Jennifer] distinctly called out [Jaiden] and said, ‘See, you didn't have a spoon with you. If I wasn't prepared, you couldn't have eaten.’ [Jaiden] responded with a smile, grateful for the fact that he had someone to rely on...”

Marisa describes an experience in which she overhears a conversation between Jennifer and another Growth staff. She highlights Jennifer’s comment, which emphasizes Jaiden’s reliance on Jennifer to eat because he has forgotten a spoon. Marisa interprets

Jaiden’s smile as gratitude for “someone to rely on.” It is this interaction and her interpretation of how Jennifer and Jaiden are positioned in a relationship of carer to cared-for that enables Marisa’s reflection. She continues:

> “I felt like these professionals viewed themselves as responsible for these fellows. I got the sense that these fellows were helpless, that they were dependent, that they required extra care. There is a major difference between someone who requires a different type of educational method than one who is seen as entirely helpless. At the same time, I felt like the fellows were open to the idea of being helped. None of them rejected the extra support…”

As she reflects on the interaction, Marisa negotiates varied possibilities for understanding the meaning of the staff discussion and actions, as well as how meaning is being made about disability. Marisa notes that the fellows were positioned as needing “extra care” and then differentiates between simply needing an educational tweak or different method and being viewed by others as “entirely helpless.” Because Marisa hedges her wording with “as seen as” rather than stating that the person is helpless leads us to believe that Marisa is beginning to think through a critique of how it is the positioning of the fellows that cause them to be dependent on the staff, rather than actual dependency. Marisa also poses the possibility that the relationships of caregiver/cared-for are welcome and not necessarily resisted by fellows (even as they are positioned as dependent). Jaiden’s forgotten spoon is turned into a hyperbolic expression of his need for care. Jennifer uses the interaction to reify his need for “extra care” that requires her and other staff to be “prepared for everything and anything.” Jaiden’s presumed appreciation of the spoon is interpreted as acceptance of paternalistic care, ending the cycle in which his dependence is reified.

Marisa, however, continues the reflection to question the positionality ascribed to Jaiden in this interaction:

> “The [program staff] have good intentions to help these fellows out, but… they have been trained to deal with these fellows in a *professional* manner… These people are viewed [by them] as different, so different, in fact, that they need to be dealt with more like subjects and less than humans.”

Here, Marisa considers the impact of the training and professionalization of program staff and teachers. The “good intentions” of staff to “help” are in contrast—denoted by her use of “but”—with a “professional” manner, which she italicized in the original entry. Marisa connects the ways that “training” programs that prepare people to work in disability fields frame the person with a disability as a “subject” in need of care. Her reflection echoes a view of care that is “demonstrated by forcing students to achieve the skills and acquire the knowledge that has been prescribed for them… [by] making students do what is thought to be good for them” (Noddings, 2005a, p. xiv). Nodding’s ethics of care instead advocates for a version of care that requires being responsive to the authentic desires of those being cared for.

Kelly and Chapman (2015) use several case studies to describe the complicated and often adversarial, but sometimes allied, relationships that are created between disabled people who require assistance and their caregivers. The authors explain that frequently professionals see themselves as allies and as being helpful, however they are not always interpreted as such by those receiving care. In one of the cases, Shauna, who has a physical disability, explains that she prefers to hire untrained attendants from unexpected places, like a local video store, instead of from professionalized services, which emphasize medicalization of disability and compliance. Shauna feels that hiring people she can train herself is a better way to subvert the power imbalances she may experience with her hired attendant. Similarly, Kröger (2009) states that many disability activists would rather hire assistants with no qualifications because "professional education has been accused of creating a patronizing attitude and prejudice among care workers" (p. 409). Similar to these authors, Marisa is beginning to identify—in practice—problematic roles that are embedded into professional training programs, particularly where there is little say by the disabled clients in the training or hiring of caregivers. She references Kalyanpur and Harry's (2012) critique of the role that professional expertise plays in alienating families during education planning throughout her reflection. Marisa's contemplation of the professionalized roles that Growth staff exhibited may suggest that cripped fieldwork is supporting her to "spin" an understanding of the care practices she sees as problematic rather than helpful.

Marisa is beginning to understand that the deficit-oriented perspective that staff like Jennifer use to respond to disabled adults, like Jaiden, mean that the type of care that is given is subjugating rather than humanizing:

> "Upon further thought, I wondered what the most reasonable approach for having people diagnosed with a disability be more accepted in society [*sic*]. Perhaps the best way to do that is through constant exposure and experience with people with disabilities. That enables society, including professionals, to understand these people at a more personal level. It allows them to be seen as human, and not as problems in need of solutions. The approach should not be how to make a student with a disability function in a normal society, because that already carries the negative connotation that these students will have difficulty doing so, but instead, it should be an accepted fact that these people are just as capable of functioning in a society. I believe we also need to grant these people more independence, so that they can learn how to deal with situations, which would, in turn, open up job opportunities other than bagging groceries or baking groceries."

In this paragraph, Marisa considers alternative possibilities for supporting the development of a caring and humanistic approach towards understanding people with disabilities. She concludes that one approach to reach this goal is to increase the inclusion of people with disabilities in society, which would in turn change the perspective one takes on the "other." She also advocates against an assimilationist approach to inclusion. In other words, Marisa does not feel the best way for one to learn to "care" for another is to require them to become more "normal," but instead we should adapt and adjust our social arrangements to be more flexible and open to different ways of being. She concludes that social acceptance of fellows may begin with their increased independence.

Of the concept of independence and care, Kröger (2009) states that, "Disability research emphasizes rights, justice and independence whereas the ethics of care writers want to go beyond individualism and rights-based thinking and underlie the collectivism and interdependence of all people" (p. 406). Various scholars advocate for the development of reciprocal and interdependent notions of care that support the independence and rights of the person with a disability with the acknowledgement that care and support may be needed (e.g., Morris, 2001). The approach to reaching this balance must be humanistic in order to understand the needs and desires of the person who is being assisted. It appears that Marisa is beginning to grapple with these complex ideas as she develops relationships with and observes the positioning of fellows, such as Jaiden. The fieldwork experience provided an opportunity for her to contemplate and raise questions about varied meanings of care, as aligned with theoretical concepts related to care and conceptions of ability.

Ending Points: Toward Caring Relationships

Teacher Candidates expressed notions of care throughout the journal entries and although some candidates held onto particular notions of care consistently over the course of the journals, there were clear, even if subtle, trends that suggest shifts from "giving" frameworks of care to one of mutuality and reciprocity. Learning through perceiving one's own relationship with fellows as peers and friends was clearly expressed. For instance, Olivia describes that when she began the work she had approached:

> "The project very scientifically… In other words, I was looking at the whole fellowship opportunity as a student would look at yet another college assignment. However, at risk of sounding cliché, I could never have imagined how deeply personal and fulfilling this experience would end up being for me… I did not anticipate making such profound connections with everyone involved. In fact, as the weeks went on, each session felt less like an assignment and more like a hangout among friends."

The relationships that were created are described, as well as the notion that Olivia developed a caring attitude for the wellbeing of the fellow as a whole person. Similarly, Ava describes her progress from being nervous to developing:

> "…A deep sense of caring for the well-being of the fellows…. I went from being worried about what they would be like to being insatiably curious about their personalities, backgrounds, strengths, and weaknesses. I can't help but think of how much better society would be as a whole if everyone could have the experience that we are having. I think people would be a lot nicer and more empathetic towards people with disabilities if they got to know them on the level that we are."

She extrapolates the development of a caring and empathetic relationship to the larger goals of societal inclusion through exposure to caring relationships. As Olivia describes "profound connections" and Ava notes becoming "insatiably curious" about fellows, they illustrate dispositions of receptivity and engagement toward individuals with significant intellectual and developmental disabilities that characterize caring relationships, beyond beneficent orientations to care.

Discussion

Based on their writing, teacher candidates increasingly understand care as interactional as they developed relationships with disabled early adults over their fieldwork with the IAC. Marisa notably pays close attention to interactions in order to contemplate care, while other exemplars highlight connection and concern for the wellbeing of fellows. Many other journal entries describe instances where teacher candidates and fellows learned about and alongside each other through exploring the campus, similarly suggesting relationships as key to the experience. As teacher candidates developed relationships with fellows, their contemplations about care and their interactions with fellows deepened. We do not suggest that teacher candidate learning was necessarily linear, despite our organization of a progress narrative here. We do propose, however, that the length and character of the fieldwork allowed space for relationships to develop that is not typically possible in school settings that are more likely to be structured by less flexible curricular goals and traditional student-teacher positionalities. Time and depth of experiences seem to play a factor in teacher candidates learning—Olivia, for example, marks change “as the weeks went on” and Ava’s sense of getting to know the fellows “on the level that we are” suggests unexpected depth.

Preliminary analysis indicates that teacher candidates direct their varied feelings and orientations in ways that did not always indicate clear or expected correlations between feelings, orientations, and ideas for action. Engagement in peer relationships did not interrupt all dominant discourses that influence paternalistic perspectives in disability and education. Thematic analysis is adequate to laying out the ideas that are present, yet the journals illustrate a mélange of many possible orientations and actions related to common disability tropes that influence perceptions of care, as well as other evidence of learning emerging in the data, which require additional analytical approaches to disentangle. We noted that some teacher candidates began to see their roles as advocates, as they gained a desire to create more opportunities for people with disabilities to participate in campus life. Other teacher candidates pondered questions about discrimination and social justice.

Further research may consider differences and potential contradictions between care literature and orientations of justice, as applied to educational practice and teacher learning. Noddings (2005a) has argued that care and justice orientations are quite different, but can be mutual. Barnes, as cited by Kröger (2009) calls for “an approach to social justice capable of incorporating care as well as rights” (p. 406). Kelly and Chapman (2015) claim that in order to change adversarial relations between caregivers and those who are cared for, it makes “strategic and political sense for some activist and scholarly efforts to work towards changing the norms that govern professionalism” (p. 59).

Continued exploration of care and relationships in teacher education can yield further understanding of how caring relationships relate to social justice education. Central to our proposal, however, is the need for continued research to understand the caring relationship in teaching, with particular attention to the ways that narratives of dependence configure meanings of care in teacher education and practice in work with learners deemed disabled. We propose that at least some teacher candidates shifted from an imagined role as caregiver to reflection upon the relationships built with fellows. It is important to consider how this learning experience may influence their identities and practice as novice educators.

Conclusion

In this study, we present findings that illustrate the potential for teacher candidates to shift ideas about early adults with intellectual and developmental disabilities as recipients of benevolent care toward more relational notions of care through engagement in field experience that emphasized peer relationships. Teacher candidate journal entries provided insight into how they conceptualized care as part of a beginning student-teacher identity and the types of field experiences that spurred them to contemplate, reflect, and raise questions about the nature of care interactions and positionalities of disabled individuals. As several teacher candidates initially described images of a one-sided, benevolent provision of care, we saw these notions shift as teacher candidates and fellows developed relationships and learned together. While we caution that our findings are preliminary, we propose that the “cripped” fieldwork experience, characterized by peer roles and a college rather than a K-12 or disability-only setting, enabled teacher candidates to engage with and imagine disabled individuals differently than would be possible in contexts like schools or day centers that enforce medical models of disability and discourses of dependence apparent in segregation.

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Multimedia

A Question & Answer with Helen S. Cohen, Filmmaker of States of Grace

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Abstract: This article provides a brief discussion with the filmmaker Helen S. Cohen about her process creating States of Grace, a documentary that, over the course of four years, documents the rehabilitation of a physician critically injured in a car crash. The article including what Cohen has learned about disability in the process, the remarkable reactions she has received from others who have seen the film, and how this film fits in the larger trajectory of her practice as a filmmaker.

Keywords: rehabilitation, documentary film

The documentary film States of Grace, created by Helen S. Cohen and her husband Mark Lipman, captured over the course of more than four years, intimately documents the rehabilitation of Dr. Grace Dammann, a physician who is critically injured in an automobile accident. It depicts her battle with and eventual acceptance of her condition. In her transformative experience, Grace is nurtured by the care of family and friends, particularly her partner, Furyu Nancy Schroeder (Fu), a Zen Buddhist Abbess. This article provides a brief discussion with the filmmaker Helen S. Cohen about her process creating the film, including what she has learned about disability, the remarkable reactions she has received from others who have seen the film, and how this film fits in the larger trajectory of her practice as a filmmaker.

Photo 1 Dr. Grace Dammann outside the rehabilitation facility in San Francisco. Photo credit: Mark Lipman.

RDS: As you undertook this work there surely was no way for you to anticipate what would ultimately happen. Thinking about your experience with making this film, what would you say you learned about disability in the process? And how might you place this in some dialogue with what you might have felt about disability before making the film?

HC: The subject of *States of Grace*, Dr. Grace Dammann, is an old close friend of mine, so making the film was a deeply personal and profound experience for me. Mark (my husband and co-director/cinematographer) and I set out to witness and document a process whose trajectory was completely unknown to us. The whole realm of trauma and disability and rehab was new, and we learned a tremendous amount in the process – four and a half years of following Grace and her family in the aftermath of the accident.

I was familiar with the world of developmental/cognitive disabilities since I have a daughter who is on the autism spectrum, and I knew Sabrina, Grace’s daughter, since she was born so I [had experience with a person using] a wheelchair and/or walker [to] navigate life with some physical limitations. But documenting Grace's recovery and process of coming to terms with her severe disabilities and limitations was an eye opening experience, to say the least. Particularly watching someone who was so productive and active and independent have to deal with being utterly dependent on others for her acts of daily living – this was a humbling as well as inspiring part of the journey for me.

Since finishing the film and traveling with Grace all over the country to screen the film at conferences, festivals, and medical institutions, I've experienced another round of learning and eye-opening – really seeing what it takes to negotiate life in the world when you are in a wheelchair and dependent on others for just about everything. In addition to realizing how un-accessible things are – even things that are designed to be so! – I've also witnessed how people with disabilities are perceived or ignored or misunderstood by the public.

And I've learned what it takes to be someone's caregiver, and have a whole new appreciation for the role of family members or people who do that for a living. But Grace is pretty unique because of her Buddhist perspective, her background as a doctor, and her personality. Being Grace's caregiver when we travel has been a real privilege and honor, and we've made sure to have fun wherever we go. This is her mantra in life and I've bought into it completely!

RDS: You were obviously very close with the subjects of the film and were provided very intimate access. Can you speak a little in general terms about your methodology of creating this film?

HC: As I mentioned, Grace and I are old dear friends which is what made it possible for us to make the kind of film that we did – intimate, vérité, and observational – following the process as it unfolded with no other agenda than to witness, document, and to some extent probe the meaning, insights, and lessons that were being learned by the subjects themselves. It was quite difficult at times for me to navigate the divide between friend and filmmaker, particular during the times when the going got tough and Grace went through some very painful times.

Photo 2 Dr. Grace Dammann with directors Helen S. Cohen and Mark Lipman. Photo credit: Nancy "Fu" Schroeder.

It helped that Mark did not know her as well prior to the accident and, as cinematographer ([he was] basically the entire crew), he could just keep shooting and following the story where it took us. Mark really kept his eye on the ball and was the engine that kept the filmmaking process going throughout the nearly five years we were filming. He kept in touch with Grace about her appointments and activities and would show up to film on his own many times; we scheduled interviews with Grace, Fu, and Sabrina periodically to check in about everything, and I conducted the interviews. We used the audio from these interviews to "narrate" the film, editing it pretty seamlessly into the vérité material.

RDS: Watching your film, as a viewer, with the intimate glimpse you provide, it is very easy to become very invested in the lives of your subjects. With this in mind, are there any relevant updates about the essential people in the film that you might in general provide?

HC: I love to let people know that Grace finished her sewing! She has still not chosen to be ordained as a priest but might do so next year under the tutelage of her longtime teacher. In the meantime, she is still director of the Pain Clinic at Laguna Honda Hospital and (at age 70) has just begun a Buddhist Chaplaincy program to augment her work and credentials. She moved into an assisted living facility not far from Green Gulch about two years ago and though it was difficult to leave Green Gulch, that is working out quite well for her.

Photo 3 Nancy "Fu" Schroeder assists partner, Dr. Grace Dammann, with physical therapy at their home at Green Gulch Farm Zen Center, Marin, California. Photo credit: Mark Lipman.

Fu became the abbess of Green Gulch, meaning she is the priest who is the highest spiritual leader and teacher in the community, and is fully involved in that role. She's happy and has been able to travel to Japan and other places since the time we stopped filming. She and Grace continue to co-parent Sabrina and remain extended family.

Sabrina graduated from Pitzer College in 2016 and is living in LA working for a social service agency and loves it.

Mack the dog accompanied Grace to Laguna Honda for many more years and died peacefully this summer of old age.

RDS: Many people have experienced the sudden onset of a disability. Few people, though, in the entire history of humanity, have then had their experience meticulously documented in a public film. What has Grace said about the ways in which this experience of being able to watch her experience unfold--this documented passage of time--has impacted her life?

HC: I would like to have Grace answer this question herself, as she has done many times at Q&A's following a film screening. Some of her answers to this and other questions can be found on the film's website where we have FAQs posted https://static1.squarespace.com/static/5498c523e4b01fe317ef4786/t/569d4e409cadb6436a8c938d/1453149765447/SoG_FAQs_F2.pdf

Though it was difficult at times to have us and the camera following Grace around, especially when she was in a bad mood or feeling really desperate about things, ultimately the documentation process and the witnessing we did was a gift to Grace, and she experienced it as an opportunity to process her feelings and have a mirror held up to her for reflection.

She also very much wanted the film to have a positive impact in the world and on people going through trauma of any kind; she's been very pleased to experience the response to the film and to know that it is an inspirational and powerful resource for so many. That's been gratifying to us as filmmakers as well, and to see the film provide a whole new platform for Grace to speak and teach and advocate which she does so well.

RDS: Helen, can you mention a bit about how this project fits into the larger trajectory and intent of your practice as a filmmaker?

HC: I've been making social issue documentaries for over twenty years; my films and filmmaking aspirations have always been about social change and having an impact on issues I care about. I also am a storyteller and love the creative process of telling a story through film. I've made a series of films for kids called "Respect for All" that deals with preventing homophobia and prejudice of all kinds among school-age kids (for more information see http://openstudioproductions.com). And I've been producing another series about community land trusts, affordable housing and equitable community development. (The most recent film in the series is called *Arc of Justice*, which traces the remarkable story of the first community land trust that emerged out of the Civil Rights movement in Southwest Georgia) – very relevant given what we are going through in our country at this moment.

States of Grace is my first personal film, and is much more visually poetic and creative in its storytelling than my other work. While purposeful and fulfilling an important social mission, this film was more about watching and witnessing and seeing what happened. And the seven months of editing was a challenging and fascinating process of piecing together the story and the many layers of meaning embedded in it. The whole journey was a wonderful experience for me as a filmmaker.

RDS: You have mentioned how many people have told you how the film resonated with some of their own experiences. From your discussions with those who have seen the film, does anything stick out to you about people's reactions to the film (particularly with respect to issues of disability)?

HC: There are really so many amazing reactions and stories to share – so many times people have been in tears letting us know that this film changed their life or made them feel hopeful about how to get through difficult, painful experiences. Here's my favorite quote from a woman in a wheelchair who came to a screening at a theater and then wrote to us afterward:

> *"This film is a precious gift to the disability community, which has been hurt by many heroic expectations and misguided spiritual teachings. I think about disability rights as the hard-won right to be ordinary; 'States of Grace' reinforces that*

> *right with great compassion."*
>
> -Beth Smith, LCSW, MA, clinical supervisor, Through the Looking Glass

RDS: Anything else you wish to add?

HC: I think it's best to send people to the film's website, https://www.statesofgracefilm.com. There's a viewer's guide, FAQs, Grace's medical case history and lots more information that would be of interest to your readers. Our educational distributor is New Day Films (a co-op we are members of) and our film can be accessed there as well https://www.newday.com/film/states-grace.

Raphael Raphael is a film and media scholar focusing on the relationship of the body and media. His most recent work is *Transnational Horror Cinema: Bodies of Excess and the Global Grotesque* (with Sophia Siddique). Other writing includes contributions to Modern Language Association's *Teaching Film*(2012) and *Transnational Stardom: International Celebrity in Film and Popular Culture* (with Russell Meeuf) (2013). Dr. Raphael lectures at the University of Hawaii at Manoa. His scholarship is also informed by his own practice as a digital artist.

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Creative Works

Cancer Kung Fu: Fighting Back Through Writing and Drawing

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Abstract: Faroqhi describes the ways in which writing and drawing her graphic novel Krebs Kung Fu (Cancer Kung Fu) served as powerful coping mechanism during her diagnosis and subsequent treatment for cancer.

Keywords: graphic novel, disability studies

On September 1st, 2012, on my 6th wedding anniversary, I was diagnosed with Ovarian Cancer. The diagnosis changed me from a normal person who dreams up her life in steps within eternity to the "doomed" ones – my life's end had become a certainty. The essayist Susan Sontag, who suffered from breast cancer compared the (terminally) ill ones with people who had forever forfeited the passport of a wonderful, happy and free land - the country of the healthy ones.

Image SEQ Figure * ARABIC 1. Excerpt from graphic novel *Krebs Kung Fu (Cancer Kung Fu)*

When I heard about my diagnosis, I was shocked, incredulous, devastated, and very much afraid. My husband and I tried to hide the impact of the news from our children, we went to bed early and cried together. On the next morning I woke up, sat down for yoga and meditation as usual and decided not to give in to fear but to write a graphic novel about whatever was to come.

After all, I had become a person with a mission (overcome fear and face reality in all its aspects) under time pressure. I had become hero material. Why not make the best of it and become and draw my own story?

It took 4 years from this point to the finishing of the graphic novel *Krebs Kung Fu* (*Cancer Kung Fu*) which will be released with the German publisher Bebra in October of this year. In the meantime, I had to undergo surgery, chemotherapy and several complications and weaknesses. The goal to write a graphic novel about all of this was a good excuse not to be ashamed of my obsessiveness with every detail of the disease and its treatment.

For me, it was easier to feel lost in some waiting area or to be overwhelmed with leaden weakness after yet another chemotherapy session when I could tell myself I was some kind of witness to something universal that deserved to get recorded and told. And it felt even easier to make fun of myself and the absurdity of my fears.

The graphic novel follows the narrator (the Anna character) through her daily routine as a cancer patient, from the first indication of the diagnosis until the end of a special treatment 1 ½ years later. The character starts as a neurotic person in distress and ends as a heroine grateful to life and everyone who has helped her during the process. The reader follows the character to various talks with doctors, friends and other patients, to the hospital for surgery and treatment. You see her at home with her husband and three very different children. You see her get obsessed with food and books that could convey promises of solace or even healing. You see her fight over nothing with her loved ones, doze on for hours and meanwhile imagine herself fighting a fierce fight against nasty cancer cells. You see her pursued, laughed at and arguing with cancer death and its tiny helpers, the Evil Cells.

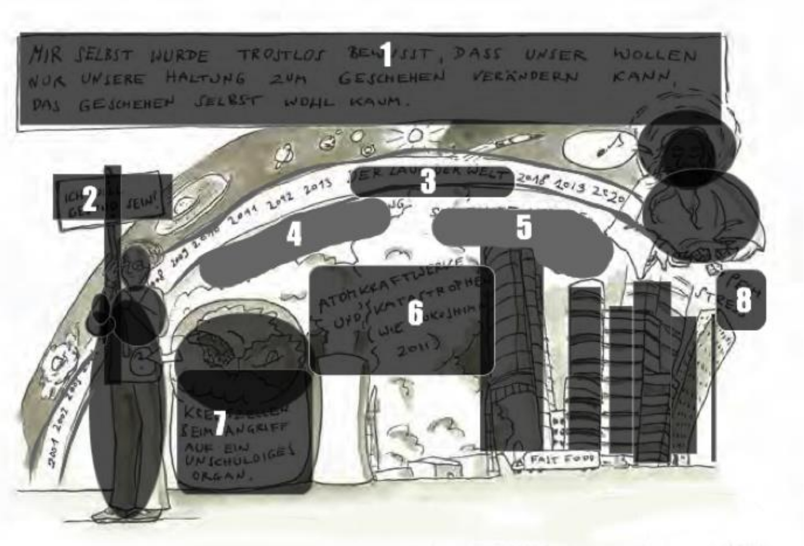

Image 2. Accompanying legend for excerpt from *Krebs Kung Fu* graphic text translation

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Translation of *Krebs Kung Fu* excerpt (Image 1)
(See Image 2 for positions of translated text in image)

1 - (beginning with “mir selbst”)
I came to the bleak realization that our intentions can only change our attitude to events, not the events themselves
2 - I want to be healthy
3 - the course of the world
4 - pollution
5 - unhealthy way of life, genes, inherited traits
6 - nuclear power plants and disasters (like Fukushima 2011)
7 - cancer cells attacking an innocent organ
8 - misfortune, stress

German-to-English translation of image graciously provided by Katharina Heyer, University of Hawaii

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As neither the heroine nor the doctors in charge can change her destiny for sure, a lot of what is being discussed is not how to fight cancer itself but how to fight the fear of suffering and death. Better: how to maintain a certain quality of life, how to remain an active character in your own life until its possible end.

The story has an open but happy ending.

For me, for the time being, it remains thus, as so far all check-ups have had the wished for results (as of Sept 2017). Ovarian cancer is an extremely dangerous cancer as it is hard to get diagnosed and when it does, you usually end up with a 50/50 chance to live or die soon.

I was often asked if humor was the correct approach to this kind of situation. For me, it is. The gravity is lifted off your own life when you have to ponder its ending.

The graphic novel allows you to find images for the most hilarious inner visions or emotional fits. If you see yourself as a green slimy monster that gradually becomes a human being again thanks to your husband's love and attention, you can ban this image on paper and thus get rid of it.

During the process of conceiving and writing the graphic novel, I got tremendous support from family and friends. The physician who operated on me, Dr. Jalid Sehouli, played a huge part in getting the graphic novel released. He is a renown specialist on ovarian cancer. Patients from all over the world seek him out for treatment. He keeps telling his patients that everything is allowed and wished for that helps them improve their quality of life. The exchange with him was invaluable to the making of the graphic novel.

For a year now, the graphic novel has been given out to patients, physicians and others who showed an interest, by a big pharmaceutical firm which has helped finance the enterprise. I have also received touching responses.

For the entire experience I am extremely grateful.

Sept. 25, 2017

Durch die Erkrankung bin ich weder klüger noch besser geworden,
nur selbstbewusster vielleicht. Wie immer es weiter geht:
sehr viel Zeit habe ich nicht zu verschwenden. Mein Wunsch
ist, das Leben bewusst und wahrnehmend zu genießen.
Mit der zeitlichen Entfernung von der Diagnose Krebs und
den Therapien kehrt langsam meine Weltoffenheit zurück. Damit
verliere ich auch meine sorgfältig aufgebaute Tod-akzeptierende-
Leben-erringende Guerillahaltung. Ich werde eine dem
Leben und seinen Zerstreuungen Zugewandte, fast wie vor der

Diagnose. Was ich aber weiß ist, dass mir dank der Unterstützung
von Ärzten, Familie und Freunden eine konkrete Lebensmöglichkeit
geschenkt wurde. Jeder Tag ist ein Geschenk.

By the disease I have become neither wiser nor better,
only self-assured perhaps. As always,
I have made the most of the time. My wish
is to enjoy life consciously and perceptively.
As the time from the diagnosis of cancer and
the therapies passes, I slowly return my regular life. To do so,
I also lose my carefully constructed death-accepting-
Life-surrendering guerrilla attitude. I return to
Life and its distractions, almost as before
Diagnosis. What I know though is that thanks to the support
of doctors, family and friends, I have received the possibility of truly living.
Every day is a gift.

Special thanks to Katharina Heyer (University of Hawaii) for translating text of graphic novel image.

Anna Faroqhi is a Berlin-based filmmaker and illustrator. She trained as a classical singer, as well as in mathematics, physics, and film. Faroqhi's body of work includes films, texts, illustrations, and educational works, and has been presented internationally in museums and art events. Faroqhi teaches video for opera directors and singers at the Hans Eisler School of Music in Berlin. She has given film seminars at the Beit Berl Film School, Israel; St. Joseph University, Beirut; Cornell University, New York, Transart Institute, Berlin; and was an advisor at the Filmuniversität Potsdam. In 2009, she was a recipient of the Villa Aurora work stipend in Los Angeles. Together with her husband and collaborator Haim Peretz, Faroqhi gives workshops in film and illustration for children and adults at various public schools, museums and institutions. The results of these workshops have been presented in public shows curated by the artist duo at museums, galleries, or movie theaters. Faroqhi sees her educational work—especially if participants come from underprivileged and/or migration backgrounds—as an empowerment for participants to voice their own stories. Anna Faroqhi's work has been shown in Berlin at the Hamburger Bahnhof, Saalbau Neukölln, Akademie der Künste, Martin-Gropius-Bau, and at the Manifesta, Italy, New York Film Archives, Goethe Institute, Tel Aviv, etc.

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