

Care, Disability, and Violence: Theorizing Complex Dependency in Eva Kittay and Judith Butler

STACY CLIFFORD SIMPLICAN

How do we theorize the experiences of caregivers abused by their children with autism without intensifying stigma toward disability? Eva Kittay emphasizes examples of extreme vulnerability to overturn myths of independence, but she ignores the possibility that dependents with disabilities may be vulnerable and aggressive. Instead, her work over-emphasizes caregivers' capabilities and the constancy of disabled dependents' vulnerability. I turn to Judith Butler's ethics and her conception of the self as opaque to rethink care amid conflict. Person-centered planning approaches, pioneered by disability rights activists, merge Butler's analysis of opacity with Kittay's work on embodied care, while also inviting a broader network of people to both interpret needs and change communities. By expanding our conceptions of dependency, feminist disability studies can continue the aim of both Kittay and Butler: to humanize unintelligible lives.

To whom it may concern:

If this letter has been opened and is being read, it is because I have been seriously injured or killed by my son, Sky Walker. I love Sky with my whole heart and soul and do not believe he has intentionally injured me. I have tried my best to get help for him and to end the pattern of violence that has developed in this home. I believe my best has not been good enough. That is my fault, not Sky's. Numerous people know about the violence and many have witnessed it. We have all failed Sky. I do not want him to be punished for actions for which he is not responsible.

Trudy Steuernagel (Connors 2009)

I met Trudy Steuernagel and her autistic son Sky in February 2006 during a graduate prospective visit to Kent State University. Trudy had taken a special interest in

bringing me to Kent. She was analyzing public policies on autism, and my master's thesis on justice interwove stories about my autistic brother. Trudy's tour was brief; we had to pick up Sky from their house. Sky immediately reminded me of my brother: teenaged, tall, and slightly overweight with a familiar sway in his shoulders that made his body bristle with energy. But unlike my brother, Sky had some language and he was joining us for dinner, something impossible for my brother due to his behavioral outbursts. We went to a local college hangout—deserted during spring break—and Sky ordered his usual: chicken fingers and French fries.

While Sky played arcade games, Trudy and I discussed autism, love, and violence. Researchers have found that over fifty percent of adolescents and children with autism exhibit aggressive behavior (Kanne and Mazurek 2011), and aggression is the strongest predictor of parental stress (Baker et al. 2002). Oddly enough, Trudy and I mostly laughed, swapping stories about our near-misses from serious injury. At his worst, Sky targeted his rage at Trudy: pursuing her through their house, tearing doors off hinges, and forcing Trudy to lock herself in a closet for safety. Our conversation, however, gave me the impression that Sky's violence had abated; Trudy described taking Sky to specialists who had regulated his behavior with medication. When we parted, Trudy embraced me in a long hug and Sky slapped me a high five. I chose not to attend Kent State, but I held fast to the memory of Sky and Trudy. Although they faced challenges, I presumed Trudy and Sky were living happily together.

Four years later, sheriff's deputies discovered Trudy beaten, unconscious, and barely breathing on her kitchen floor and Sky in the basement, blood splattered on his pajamas. Trudy died eight days later. A year after his mother's death, Sky lived in a locked facility with two personal assistants overseeing him at all times. Family members suspected that Sky understood what had happened, finding evidence in his words, "Sky sorry hit Momma."

After *The Plain Dealer* published Trudy's story, American novelist Anne Bauer published "The Monster inside my Son," which vividly described her autistic son's aggression and her family's difficult decision to institutionalize him (Bauer 2009). Online, many parents identified with her abuse. "My son is 22 and has autism, mental retardation and is non-verbal," wrote one mother. "He has gotten quite violent with me in the past, severely and repeatedly slamming my head into the floor or head butting me until I was able to escape." Bauer says, "We cannot solve this problem [of violence] by hiding it, the way handicapped children themselves used to be tucked away in cellars." Bauer described her story as "[breaking] the silence," suggesting that this form of domestic abuse is especially invisible.

Other responses, however, attacked sensational accounts of autistic people as violent "monsters." These posts accused Bauer of adding to the stigma of autism, of linking violence to autism by means of poor data, and of failing to understand the "why" behind violence. These respondents argued that emphasizing the violence of a small minority of disabled people is prejudicial, especially as it ignores appallingly high rates of physical, emotional, and sexual abuse against people with disabilities—most of which goes unreported.

Trudy's death thus stirred conflicting reactions around issues of care, violence, and disability—issues that remain outside dominant discourses around disability and dependency in feminist disability studies. Indeed, people with disabilities and their families in abusive relationships will find little in care literature or disability studies that acknowledges their experience. This absence is especially problematic in care theory, given care ethicists' adherence to concrete and particular experience, and because of the influence of Eva Feder Kittay's work on care ethics and disability. Care ethicists, no doubt, offer us important insight into these crises. Their work politicizes the needs of dependency workers and disabled dependents—two figures ignored by mainstream philosophy—and shows how our collective denial of dependency leads to political lacunas that induce these crises of care, such as the paucity of residential options for adults with disabilities.

In this paper, I focus on the experiences of caregivers abused by their children with autism to illustrate how Kittay's influence over-determines the philosophical conversation about people with developmental disabilities and caregivers. In *Love's Labor*, Kittay explains that her focus is on "extreme dependencies" in order to resist the dominant "pretense" of independence (Kittay 1999, xii). An unintentional consequence, however, is that Kittay's emphasis on *permanent* vulnerability forecloses the possibility that dependents can be both vulnerable *and* aggressive. This foreclosure silences experiences of violence and leaves us unequipped to respond to abuse.

Departing from Kittay, I argue that Sky represents a model of *complex dependency* in which individuals inhabit both intense vulnerability and aggressive power. My article builds on recent feminist work intent on decoupling care theory from the valorization of care (Cloyes 2002; Sander-Staudt 2006; Cooper 2007; Pettersen 2012; Kelly 2013). I turn to Judith Butler's ethics, as well as to person-centered planning approaches pioneered by disability rights activists, to rethink care ethics amid complex dependency. Both show us how human selves are opaque to one another and to themselves—an opacity that troubles Kittay's depiction of the relationship between caregivers and dependents. My intention is not to emphasize the violence of some bodies over others, but to show how narrow portrayals of disability and dependency render some lives unintelligible within feminist disability studies.

ROMANTICIZING CARE

In arguing that Kittay's care theory idealizes caregivers and dependents, I depart from most criticisms of ideal theory that attribute problems of idealization to theoretical abstractions (O'Neill 1993; Mills 2005). In the traditional debate between justice and care, theorists associate liberal theories of justice with abstraction and care ethics with the concrete and particular. For Onora O'Neill, liberal theories "appear to apply widely, but...covertly exclude those who do not match a certain ideal" (O'Neill 1993, 310). Indeed, Kittay describes care ethics as a "non-idealizing theory" because it "is especially responsive to the actual narratives and practices of care [and] aims to

be inclusive of all” (Kittay 2009b, 122). Kittay criticizes philosophers for idealizing cognitive abilities, which devalues people with intellectual disabilities. Like O’Neill and Charles Mills, Kittay worries about who and what gets silenced by ideal theory (122). Nevertheless, although Kittay’s care theory is *not* an ideal theory insofar as she avoids abstraction, she idealizes human dispositions in ways that threaten to marginalize some caregivers and dependents.

Kittay emphasizes the difference between ideal theory and care ethics by contrasting a Rawlsian-inspired original position of care—a hypothetical desert island populated solely by an adult caregiver and an infant—to her own philosophical starting point of her experience mothering Seshu, her intellectually and physically disabled daughter. Unlike in the case of the abstract infant, webs of human connection define Seshu’s life, and it is this very real starting point of dependency that animates Kittay’s work, providing “a tether that prevents me from wandering away from the lived reality” (Kittay 1999, 162).

But abstraction is not the only path to idealization. As Davina Cooper suggests, care theorists harbor a similar “gravitational pull of an ideal conception of care” (Cooper 2007, 254). In contrast to idealizing-as-abstraction, care ethics can idealize-by-romanticizing. To romanticize is “to make (something) seem better or more appealing than it really is.” Liberal accounts idealize the human capacities of the atomistic individual, and care theorists romanticize human capacities to maintain relationships. Kittay romanticizes care when she depicts loving experiences of care, thus obscuring the everyday struggles of carers and dependents.

TRANSPARENCY MYTHS

Problems of idealizing care arise in part from Kittay’s account of the caregiver and the way she privileges the ideal of transparency. Transparency is the idea that a dependency worker should be able to interpret and reflect the needs and desires of the dependent while her own needs and desires recede. For Kittay, “The perception of and response to another’s needs are neither blocked by nor refracted through our own needs and desires” (Kittay 2007, 53). The transparent caregiver separates the needs of her charge from her own interests, ensuring that the care she provides is uncorrupted by self-interest.

Kittay sets aside whether this conception of the transparent self is desirable and argues instead that the realities of care make the transparent self “indispensable” (Kittay 1999, 51). Although “no self is ever truly transparent in this sense,” transparency provides “a benchmark for the self-conception of the individual who cares for a dependent person” (52; Kittay 2013, 312). Kittay admits that this benchmark may seem “insurmountable” and “especially challenging when the person being cared for cannot be explicit in communicating needs and interests” (Kittay 2011, 615). Additionally, Kittay describes transparency as a never-ending ideal that caregivers should emulate, as the “effort of preserving a severely disabled child’s life is often accompanied by a *lifelong* commitment to day-to-day *physical* care for the

child” (Kittay 1999, 165; her emphasis). It is “precisely” in cases of profound intellectual disability that Kittay argues “we need such stringent requirements” (Kittay 2011, 615). Without transparency as a benchmark, the carer could simply use her own needs to guide care, potentially arguing that her charge would rather be dead than disabled.

Carers of people with profound mental impairments with little to no ability to communicate their needs face a twofold transparency dilemma. First, they must decipher the person’s unspoken interests, desires, and projects. Second, they must disentangle the desires of their charge from their own. “But in such an intimate relationship,” Shiloh Whitney questions, “what interests are *only* the interests of the charge?” (Whitney 2011, 564). Whitney argues that the ideal of transparency violates the relational ontology at the core of care theory, in which identities and interests are not autonomous, but rather interwoven. The dependency worker’s ability to segment interests—her own and her charge’s—neglects how these interests overlap and produce each other.

In this regard, Kittay’s transparent self closely resembles the liberal self from which her theory means to depart. Both selves idealize cognitive capacities. Whitney argues that the transparent self “revolves around a center just as surely as the liberal person, only it is a requirement of Kittay’s transparent self to import the content of its center—interests, needs, projects, desires—from another” (Whitney 2011, 564). Although the aims of knowledge and the sources of transparency shift between the liberal and transparent selves, they share an unrealistic range of cognitive capacities. Mills’s critique of ideal theory—that “human agents as visualized in the theory will also often have completely unrealistic capacities attributed to them” (Mills 2005, 168)—applies to Kittay’s conception of transparency as the carer is able to detach herself from her own interests. Mills charges ideal theory with creating an idealized cognitive sphere in which “social transparency will be presumed, with cognitive obstacles minimized” (169). For Kittay’s carer, the obstacle minimized is her disabled and nonverbal charge.

The relationship between Trudy and Sky reveals problems behind transparency, particularly how the physical demands of care threaten to distort the cognitive demands of transparency. According to Trudy, “I couldn’t be a friend to anyone because I physically and emotionally could not be there for them” (Connors 2009). If Trudy was too exhausted to be a friend, could she likewise engage in the constant cognitive task of deciphering Sky’s (unspoken) interests, and then separate her interpretation of his needs from her own conscious and unconscious desires? The demand for transparency can thus isolate a caregiver and make transparency impossible, since the carer becomes so isolated in the act of trying to achieve transparency that her own needs, relationships, and life are lost. Kittay recognizes these demands: her concepts of *doulia* and distributed mothering serve the needs of caregivers. Although added support systems would have been beneficial, Trudy also required a clear acknowledgment of her own physical and mental limits—that no amount of dedication could enable her to know fully Sky’s needs, desires, and future actions. Or, for that matter, her own.

COMPLEX DEPENDENCY

These conflicts never materialize fully in Kittay's care ethics because she theorizes disabled dependents as loving, vulnerable, and powerless. Drawing on her daughter as a paradigmatic example of extreme dependency, Kittay describes Sesha as possessing

the most important faculties of all. The capacities for love and for happiness. These allow those of us who care for her, who love her, who have been entrusted with her well-being to form deep and abiding attachments to her. Sesha's coin and currency is love. That is what she wishes to receive and that is what she reciprocates in spades. (Kittay 1999, 152)

The centrality of forming loving connections between carer and charge accomplishes important theoretical work for Kittay. Connection enables and sustains transparency (186). Presumably, only by forming a deep connection with someone can we begin to decode her interests, especially when that person is nonverbal, and this connection helps sustain the unending task of transparency. Most important, the ability to reciprocate with love proves that Sesha exercises human faculties and is therefore fully human.

When describing other people with cognitive disabilities, Kittay similarly draws our attention to their ability to reciprocate emotionally as a way to debunk Jeff McMahan's assertion that people with cognitive disabilities "lack self-consciousness [and] are almost entirely irresponsive to their environment and to other people" (quoted in Kittay 2009a, 228). Kittay describes seeing a man with intellectual disabilities show no sign of sadness when his mother and sister told him his father had died, but once his family left, he began "howling [and] wailing" (229). Kittay interprets his delayed grief as compassion for his family, concluding, "so much for cavalier claims that the severely retarded cannot form profound attachments" (229).

Other philosophers eager to prove the humanity of people with cognitive disabilities similarly emphasize disabled people's positive traits. Michael Bérubé points out the problematic nature of hinging inclusion to idealized accounts of emotional reciprocity, but his own work counters ableist prejudice and the work of Peter Singer by describing the many talents of his son Jamie, who has Down syndrome. Bérubé recounts Jamie's love of the Beatles and science fiction, and his passion for learning a foreign language with which he charms young women (Bérubé 2009, 353). Similarly, Martha Nussbaum's *Frontiers of Justice* draws on the examples of Sesha, Jamie, and her nephew Arthur. Nussbaum describes Sesha as "Attractive and affectionate, she loves music and pretty dresses"; Jamie as having a "sly sense of humor"; and Arthur as "a big good-looking ten-year-old boy" who can talk endlessly about the theory of relativity (Nussbaum 2006, 96, 97). Nussbaum discusses Art's impairments—including his fear of strangers, "distracting bodily tics," and a penchant for making "weird noises"—but these are countered with more positive traits (97).

The philosophical value of these familial examples takes on heightened importance when we consider how other philosophers incorporate them into their theories. Indeed, Sesha travels well beyond Kittay (Stein 2007; Arneil 2009; Parens 2009;

Barnes 2011). Used as such, they become shared philosophical cases of intellectual and developmental disability that—although well intentioned—are unrepresentative. All of them are philosophers' loved ones; apparently none are aggressive. We see them as talented and loving with their own set of (knowable) desires and passions with little attention to difficulties that may arise from challenging behavior, financial strain, or emotional and physical isolation.

Particularly for Kittay, vulnerability defines the disabled dependent and her relationship to others. Dependency relations, for Kittay, “begin with the needs of a charge who is vulnerable” (Kittay 1999, 64). The vulnerability of dependents eases the burden of transparency as the caregiver is able to “forgo one's own best interest for the sake of another who is entirely vulnerable to one's own actions” (186). Because Kittay depicts the vulnerability of disabled dependents as permanent, then powerlessness becomes an enduring condition of disability. “The individual with severe disabilities does not outgrow a profound vulnerability, nor can she assume the task of her own self-preservation” (165). By characterizing dependency as permanent and by depicting dependents as always loving, Kittay presents a static picture of developmental disability.

Occasionally, Kittay acknowledges that her positive presentation of Sesha to the public is the result of her own conscious desire to soften other people's repugnance. Kittay describes dressing Sesha to be as pretty as possible to garner affection in public. Or she avoids appearing in public with Sesha, thus escaping stigmatizing stares. “I don't want to see Sesha as others see her. I want them to see her as I see her” (166).

Kittay's idealization of Sesha is understandable when we situate her work within a discipline that routinely dehumanizes people with disabilities. In this context, any admission of negative traits would seemingly prove the opponent's point: that people with developmental disabilities are more animal than human. Although Kittay has fought long to humanize her daughter to an uncaring audience (Kittay 2009c), we have to ask how these idealized accounts of personhood exclude nonconforming individuals and mask alternative experiences of care.

Kittay considers briefly the effect of nonaffectionate dependents. “In comparison studies with autistic children,” Kittay writes, “researchers have found that ‘the mother's ability and enthusiasm for functioning in the maternal caregiver role are adversely affected by the developmentally disabled child who is *not* affectionate and *not* demonstrative” (Kittay 1999, 154, quoting Wikler 1986, 184; Wikler's emphasis). But Kittay quickly points out that researchers “also found (to no one's surprise I hope) that the greater degree of ‘incapacitation and helplessness,’ the greater the burden the child poses” (Kittay 1999, 154–55). In an odd move in disability's race to the bottom, Kittay seems keen to demonstrate that the physical disability of Sesha is equally if not more burdensome than the emotional detachment of autism.

Aggression, however, exceeds emotional detachment. Teachers and parents of autistic children find that “conduct” problems—including defiance, disobedience, and aggression—cause the most stress (Lecavilier, Leone, and Wiltz 2006). Trudy related similar problems: “Sky's senior year started with seven official reports of aggressive episodes and use of physical restraints and police calls. His food obsession, a common

factor in autism, had gone out of control” (Connors 2009). Sky was not the eternal spring of love like Sesha, nor did his quirky obsessions lead to tedious discussions about airplanes. Rather, his aggressive and obsessive behavior isolated him and Trudy in the last year of Trudy’s life.

I met Sky only once, a few years before he killed his mother, but he fits neither McMahan’s crude caricature of consciousnessless nor Kittay’s idealization of love. Instead, Sky is a complex person with a very complex set of impairments. Like my brother, Sky has moments of tenderness, love, and affection. But these traits fail to define him. And like my brother, Sky is not entirely powerless. He buttresses his limited verbal ability with physical communication such as tugging on arms, flipping hands, and spinning, but also more destructive forms, such as self-injurious behavior and injury to others.

People like Sky and my brother experience complex dependency as opposed to Kittay’s model of dependency as vulnerability. In complex dependency, dependents find ways to exercise power amid vulnerability. Because Sky lacks language, he is more vulnerable to abuse. His aggressive behavior, however, means that those who provide care are also vulnerable to him. Both Sky and my brother live in state-run institutions and, as such, they are vulnerable to the people who provide their care. For those of us who follow the news about developmental disabilities, we are sadly accustomed to routine stories about institutional abuse, physical and sexual, that sometimes causes death. Surely, people with developmental disabilities are vulnerable, but so too are the people who surround them, both paid attendants and fellow residents. For Sky and my brother, disability is not interchangeable with vulnerability. Treating them as such fails to see them as the complicated and fully human individuals that they are.

CONFLICTUAL CARE

We need a model of care that tells us how to cope and respond to conflict and complexity (Tronto 2010), not how to make ourselves transparent or vulnerable. In fact, Kittay offers us an alternative model when she describes her relationship to Peggy—Sesha’s paid dependency worker—and the complex negotiation of power that accompanies their relationship.

In passages about Peggy, Kittay acknowledges that Sesha’s needs are impossible to interpret fully, and she describes how her relationship with Peggy fractures under mounting stress. Significantly, Kittay attributes these conflicts to difficulty in discerning Sesha’s needs. “When Sesha is ill, we don’t know what bothers her, what hurts her, what the pain feels like. We are deprived of a vital avenue for diagnosis. This makes her so vulnerable, and makes us crazy” (Kittay 1999, 159). Instead of transparency, this passage reveals two women struggling to interpret Sesha’s indecipherable needs. Kittay and Peggy’s frustration breeds fear and anger at each other, as each woman suffers under the strain of being inseparable from Sesha’s daily care and their concomitant fears about the future.

Kittay also describes how she struggles internally with the unequal distribution of power between herself and Peggy, which a doctor's appointment for Sesha reveals. While Kittay converses with the doctor and makes decisions, Peggy provides hands-on labor, situating Kittay within a familiar gendered hierarchy. Briefly, Kittay acknowledges the discomfiting power dynamics involved. "Sometimes I feel that my relationship to Peggy vis-à-vis Sesha is like the patriarchal relation of husband to wife vis-à-vis their children" (Kittay 1999, 160). Kittay avoids elaborating on these struggles, and we lack Peggy's voice explaining how she feels about her relationship to Kittay or Sesha, but we see from this passage a system of distributed care that is fraught with conflict.

This is not transparency; this is struggle. Struggle deciphering Sesha's unknowable needs; struggle navigating uncomfortable power dynamics with Peggy; and struggle with Kittay's own role, as it is bound with power and uncertainty. Although I do not know what it feels like to be a transparent self, I am familiar with conflicts that arise from trying to interpret the needs of someone entirely nonverbal. As I was growing up, my family divided care for my brother between parents and siblings. When my brother cried, five people pronounced a different cause. My mother blamed sickness, my father blamed boredom, I blamed my parents, my sister looked to the weather, and the other sister consulted the phase of the moon. Not only did we struggle to determine my brother's needs, but we also struggled with the ways in which our family's distributions of power—not transparency—resolved these disputes.

Kittay insists that providing the best care requires consulting others, but again, her aim is to increase transparency rather than to negotiate conflict. She suggests that parents should seek out opinions of the disability rights community "because people with disabilities help parents become more transparent to the needs of their child" (Kittay 2011, 615). Kittay ignores how consulting disability rights activists may reveal conflicts without resolution. As with my own familial dynamics, interpretation is not univocal, but results in a cacophony of needs and remedies. Where does a model of care begin that remains open to conflict?

PRIVILEGING OPACITY

Judith Butler's turn toward ethics invites us to rethink aspects of care ethics, as her emphasis on opacity troubles Kittay's regulatory ideal of transparency. In *Precarious Life*, Butler takes up issues central to care theory—vulnerability, dependency, and responsibility—but seldom discusses care ethics or disability. Like Kittay, Butler explores how our "primary vulnerability to others" motivates both ethics and violence (Butler 2004a, xiv). By coupling Butler and Kittay, my analysis pushes on elements of Butler's ethics, particularly her linguistic focus, her reading of the body as a site of agony, and the limits of recognition as a moral response—all of which Kittay helps us rethink.

Whereas Kittay begins with relations of dependency to conceptualize vulnerability, Butler chooses grief to explore how we are vulnerable to others and how our

identities are not autonomous. Accordingly, we are “given over from the start to the world of others [and] only later, and with some uncertainty, do I lay claim to my body as my own, if, in fact, I ever do” (Butler 2004a, 26). By being “given over” to myself, I cannot claim that all of my desires are strictly my own. In *Giving an Account of Oneself*, Butler describes us as opaque to our selves and others; hence, we can never understand fully the other’s needs or our own investment in the other.

Reasons course through me that I cannot fully recuperate, that remain enigmatic, that abide with me as my own familiar alterity, my own private, or not so private, opacity. I speak as an “I,” but do not make the mistake of thinking that I know precisely all that I am doing when I speak in that way. (Butler 2005, 84)

Significantly, “to acknowledge one’s own opacity or that of another does not transform opacity into transparency” (42). Care theorists should recognize that the care I offer, and the care I receive, springs forth from these partial and sometimes misguided narratives. Although care ethicists like Joan Tronto recognize that our “perceptions of needs can be wrong” (Tronto 1995, 108), Butler’s opacity suggests that in almost all cases our perception cannot be relied on to be right. Under Butler’s view, Kittay cannot access entirely Sesha’s needs because she can never decipher her own.

Desires for transparency are never innocent for Butler. Instead, transparency performs “a certain ethical violence, which demands that we manifest and maintain self-identity at all times and [requires] that others do the same” (Butler 2005, 42). In attempting to have mastery over knowledge of another, we foreclose the ways in which identities are never closed but always in flux. In contrast, when opacity grounds our relationship with another we make room for each other—room to flourish, regress, hurt, and surprise. For Butler, “If letting the Other live is part of any ethical definition of recognition, then this version of recognition would be one that is based less on knowledge than on the apprehension of epistemic limits” (43). In accepting limits, I acknowledge that the care I give and receive may be clumsy or unwise and I may not know it. Consequently, forgiveness is central in Butler’s ethics as “I will need to be forgiven for what I cannot fully know, . . . and I will be under a similar obligation to offer forgiveness to others who are also constituted in partial opacity to themselves” (43).

Examining relationships with Sesha and Sky reveals how developmental disabilities intensify these human predicaments, as carers construct narratives about Sesha and Sky without the other’s words. Butler’s emphasis on narrative in *Giving an Account of Oneself* emphasizes linguistic communication, and sidesteps the ways in which some selves lack the ability to narrate their own selves. This linguistic emphasis threatens to leave uncontested the ungrievability of people who are nonverbal due to disability. Although Butler acknowledges that embodiment heightens our opacity (Butler 2005, 38–39), language governs her theory of the self and opacity.

When Butler explores embodied and nonverbal modes of communication, she describes “bodily parts” that “are said to cry and to sob and to scream” (Butler 2004a, 133), thus establishing our embodied vulnerability as wounds awaiting exposure.

Bodies evoke agony, but they also express joy, love, and connection. Kittay's work allows us to see care and love as alternative bodily speech acts, and how relationality exceeds narrative. Additionally, Kittay's focus on disability makes us skeptical of accounts that render the body an endless site of agony as disabled bodies too often symbolize pain, suffering, and death. Kittay offers us a positive account of embodied expression and disabled embodiment.

Care theorists also complicate Butler's ethics, as their emphasis on the *practice* of care—rather than recognition—suggests how we are required to act amid opacity. Butler argues, “recognition sometimes obligates us to suspend judgment in order to apprehend the Other” (Butler 2005, 44), but care ethicists' emphasis on practice troubles our ability to suspend judgment indefinitely. Consider the four phases of care outlined by Tronto, which encompass interpreting the other's needs, taking responsibility to give care, providing care, and reflecting on the adequacy of the care received (Tronto 1995, 142). Following Tronto, Butler's recognition falls within the first phase of care, which “involves the recognition in the first place that care is necessary” (Tronto 1993, 106). Although I can recognize another without identifying an obligation to care, when I perceive that care is necessary, then theorizing recognition as the end of ethics comes up incomplete.

CONFLICTING PATHS

Disability invites us to ask, how might we incorporate Butler's opaque self into Kittay's care theory? Disability rights activists and allies offer us an alternative model of care that aims to capture the full complexity of individuals while also building a dispersed net of allies. For example, PATH (Planning Alternative Tomorrows with Hope) is a person-centered, “team-facilitated graphic planning process” in which two facilitators guide a group of people to develop a comprehensive life plan with and for a person with a disability (Wetherow and Wetherow 2002). One facilitator guides the discussion—asking a series of questions about the focal person's life—while the other facilitator graphically represents the discussion on a ten-foot piece of paper. Like Kittay and Butler, PATH is committed to making nonnormative lives more possible and communities less violent. My interpretation of PATH as a practice embodying conflictual care draws on PATH manuals and my own training as a PATH facilitator (Clifford 2012).

Like Kittay's caregiver, PATH starts by interpreting the needs and desires of a person with a disability, but instead of the regulatory ideal of transparency, PATH's process encourages multiplicity, as facilitators encourage different perspectives to emerge. Facilitators encourage the focal person and his/her family to invite a wide range of participants—family members, community members, neighbors, friends, religious leaders, and acquaintances—to elicit a more complex understanding of the focal person. As Butler's work reveals, we disclose ourselves differently to different people. For example, if Sesha were the focal person, we would expect that Sesha would appear different to those positioned differently to her—to Peggy, her mother, her father,

brother, and neighbors. Multiple perspectives can help dispel romanticizing impulses within caregiving accounts that may privilege loving experiences and neglect traits like aggression or relational discord. By engaging a diverse set of people, PATH recognizes the epistemic limits of each individual.

Kittay's work suggests that all these differences somehow cohere to promote a truer sense of transparency for the caregiver. But PATH's practices, which require people to deliberate periodically, to maintain blank spaces on the paper, and to graphically represent different interpretations, allow these tensions to persist visually over time. By inviting a wide array of people, PATH redistributes responsibility and moves away from a dyadic model of care that overburdens caregivers by hinging their self-conception to transparency. Trudy could see only two options for herself and Sky: live together or move Sky into an institution. In inviting people to help interpret Sky's future, PATH enlists communities to broaden the futures imaginable for Trudy and Sky while also unhinging Sky's future from the determination of Trudy alone.

Exposing differences between our own and others' interpretations of the person we love, however, can be difficult. Care ethicists would attribute this difficulty to the relational ontology of selves; Butler would attribute it to the fact that we are both constituted and dispossessed by our relationships (Butler 2004a, 24). For both, identities are not autonomous, but rather dependent on relationships. Faced with an unfamiliar interpretation of my brother, I may begin questioning my own interpretation of him and myself. PATH facilitators anticipate these questions. In the example of Sessa, facilitators would invite participants like Kittay and Peggy to realize differences in the ways they imagine her future—differences that may reveal unspoken conflicts about power. The PATH manual thus questions potential participants: "Are we willing to face the possibility that, because important problems frequently call for shifting power arrangements and renegotiating roles and rules, we may have to deal with significant conflicts and we will certainly have to consider big changes in the way we do things?" (Pearpoint, O'Brien, and Forest 2000, 9)

In these ways, PATH's facilitators strive to create paths that exceed a single coherent narrative—and artwork is central to this creativity. Artwork pushes against Butler's pull toward linguistics that constrains self-identity, a constraint that Butler herself wants to reject. The facilitator who graphically records the conversation uses words and pictures to capture participants' beliefs while also prodding them to think more creatively. During PATH training, experienced facilitators coach trainees to fire up their own artistic imaginations. PATH's graphic planning process symbolizes how our identities, relationships, and futures strain against the closure of language. Writing a narrative presumes that the words I choose correspond to who I am, whereas an artistic representation evokes open-endedness.

Rather than tell a story about Trudy and Sky, PATH's graphic planning process could paint Sky's aspirations alongside a community of partners, friends, and family—a community largely missing, as we can infer from Trudy's letter. By reaching out to community members to take part in Sky's life plan, PATH's deliberative process aims to make his life and his future more intelligible to those gathered around him, who

must deliberate and imagine his life in his presence—in his full complexity and opacity. By creating a diverse network of supports, PATH enlists multiple allies to help integrate Sky into their home communities, workplaces, and places of worship and leisure. As Sky becomes more intelligible to his small PATH network, PATH's mission is for this network to assist the wider community in welcoming Sky. "Social transformation," following Moya Lloyd's interpretation of Butler's radical politics, "will take place where 'daily social relations are rearticulated, and new conceptual horizons opened up by anomalous and subversive practices'" (Lloyd 2007, 150, quoting Butler). PATH facilitators help participants to encourage their communities to find new inclusive practices.

Accordingly, one of the last stages of PATH—once the ten-foot paper is almost full—is for each participant to identify his or her next specific action that will be the first step of ensuring that the focal person's life plan takes effect. Facilitators encourage members to write down their next action in the presence of everyone as a way to emphasize PATH as an action-oriented process. Fostering intelligibility at times requires people to take on obligations of care. Hence, if people left the planning session with a more complex understanding of the focal person, but failed to act on the ways to help make his or her life plan a reality, then PATH is unsuccessful. Facilitators encourage participants to schedule a follow-up meeting in a month to verify who fulfilled their action steps and, for those who did not, to identify obstacles in their way. Although PATH avoids the language of care, it enlists participants in a distributed network of care—amid complex dependency.

Much of PATH's process coheres with Butler's commitment to make nonnormative lives more intelligible (Lloyd 2007, 146). Following Butler, the goal of PATH is "not to celebrate difference as such but to establish more inclusive conditions for sheltering and maintaining life that resists models of assimilation" (Butler 2004b, 4). This aim fits with Kittay's work as well, which debunks damaging tropes of disability commonly used in philosophical discourses in order to humanize disabled lives depicted as unintelligible and ungrievable. Butler endorses non-state radical democratic solutions to normative problems, and PATH's founders and promoters would agree. They criticize state-centered bureaucratic systems, as these approaches design support systems without recourse to understanding people with disabilities individually. Like person-centered planning approaches more broadly, PATH strives to bring a diverse group of people together around a person with a disability in order to foster inclusive and democratic communities.

VIOLENCE AND REMEMBRANCE

When I imagine Trudy writing her letter foreshadowing the circumstances of her death, I imagine her sense of isolation with Sky—a lonesomeness far removed from the kind of community that PATH, Kittay, and Butler envision. What kinds of community could have better nourished Trudy and Sky? What kinds of community could welcome Sky's deinstitutionalization? How can we mourn Trudy's death without

sensationalizing Sky's violence? In following Butler's belief that mourning "furnishes a sense of political community," our mourning can broaden the community of feminist disability studies by making more complex our understanding of caregivers and dependents with disabilities (Butler 2004a, 22).

But mourning is never so innocent, as Butler makes clear, and in mourning for Trudy and Sky, I have neglected other lives that remain ungrievable. Butler suggests that we mourn for lives familiar to us—lives that are "much more easily humanized"—and indeed this is true for me, as Trudy and Sky map so easily onto my own experience (Butler 2004a, 37). Although Sky troubles our philosophical examples of disability in some ways, he is also too familiar: a child of an academic, white, and middle-class. Feminist disability studies—informed by Butler and Kittay—should question how our discursive attempts to humanize certain lives silences others, and as such, perpetuates the normative violence of privileging some lives over others.

I have intentionally left violence undefined, in large part because the task of defining violence exceeds the possibilities of this paper, but also because defining violence may conceal nonconforming experiences of abuse. A feminist disability theory of violence should respond to the violence Trudy endured and question how communities could have protected Trudy from Sky. At the same time, however, a feminist disability theory of violence should resist developing norms and ideals that would compound the ways in which Sky's life is already unintelligible. How can we mobilize against violence—as Butler in *Precarious Life* suggests we do—without adding to the stigma against children and adults with autism who are violent?

Butler refers to disability in *Precarious Life* only once, when she situates people who are "physically challenged" alongside other marginalized groups who experience violence (Butler 2004a, 33). Butler's description neglects how vulnerable groups both suffer *and* perpetrate violence. Indeed, Christine Kelly argues that, because people with physical disabilities pioneered the disability rights movement, policy goals continue to neglect people with developmental disabilities (Kelly 2010). Butler and Kelly raise questions about the relationship between vulnerability, violence, and intentionality. Whose actions and bodies do we label as violent? And at what cost?

Although I want to resist defining violence prematurely, I want to conclude by raising questions about the multiple forms of violence surrounding Trudy and Sky—pushing us to think beyond Sky's violent behavior as the primary culprit behind Trudy's death. What about the violence of communities that failed to respond to domestic abuse because they were unfamiliar with autism? What about the violence that silences women and men like Trudy, who are similarly abused by dependent children? Familiar tropes around disability—the angelic child, the loving mother—silence their stories of abuse. Caregivers may prefer to stay silent when the only outcome they foresee is the violence of permanent institutionalization. Institutionalization is a profound form of state violence, which is compounded by state bureaucracies and governments that refuse to create *real* community-living options for people with disabilities. Or what about discursive violence—found in McMahan and Singer—that depict people with developmental disabilities as irresponsible and outside moral consideration? These discourses help silence people with developmental disabilities who

speak out against physical, emotional, and sexual abuse, but who are never heard, because the stigma against them makes others disbelieve their accounts.

These structural forces of violence helped create the conditions in which Trudy composed her letter, in which she foresees her death and aims to make sense of it. *We have all failed Sky*, she writes, indicting the people and conditions around her that made his life unintelligible and her own unlivable. Kittay, Butler, and Trudy push us to make marginalized lives more intelligible. If we fail to indict the structural conditions that made Trudy's death possible, then we would also miss what Kittay and Butler offer. Caregiving and dependency are risky situations as our vulnerability to one another always opens us to wounding one another. But we can lessen this risk by making our ideals and institutions contend with complex dependency.

NOTES

Special thanks to Sarah Tyson, Jennifer Nedelsky, Brooke Ackerly, Vanderbilt University's Global Feminisms Collaboration, and co-panelists at the 2012 Western Political Science Association's Annual Conference for reading and commenting on early versions of this paper. Thanks also to the DOCTRID International Research Institute and the Hegarty Fellowship for the time and space to finish this paper.

REFERENCES

- Arneil, Barbara. 2009. Disability, self image, and modern political thought. *Political Theory* 37 (2): 218–42.
- Baker, Bruce L., Jan Blacher, Keith A. Crnic, and Craig Edelbrock. 2002. Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American Journal of Mental Retardation* 107 (6): 433–44.
- Barnes, Marian. 2011. Abandoning care? A critical perspective on personalisation from an ethic of care. *Ethics and Social Welfare* 5 (2): 153–67.
- Bauer, Ann. 2009. The monster inside my son. *Salon*, March 26. http://www.salon.com/2009/03/26/bauer_autism/ (accessed May 15, 2014).
- Bérubé, Michael. 2009. Equality, freedom, and/or justice for all: A response to Martha Nussbaum. *Metaphilosophy* 40 (3–4): 353–65.
- Butler, Judith. 2004a. *Precarious life: The powers of mourning and violence*. London: Verso.
- . 2004b. *Undoing gender*. New York: Routledge.
- . 2005. *Giving an account of oneself*. New York: Fordham University Press.
- Clifford, Stacy. 2012. Making disability public in deliberative democracy. *Contemporary Political Theory* 11 (2): 211–28.
- Cloyes, Kristin G. 2002. Agonizing care: Care ethics, agonistic feminism and a political theory of care. *Nursing Inquiry* 9 (3): 203–14.
- Connors, Joanna. 2009. Kent State professor Trudy Steuernagel's fierce protection of her autistic son, Sky Walker, costs her life: Sheltering Sky. *The Plain Dealer*, December 6.

- http://blog.cleveland.com/metro/2009/12/kent_state_professor_trudy_ste.html (accessed May 15, 2014).
- Cooper, Davina. 2007. "Well, you go there to get off": Visiting feminist care ethics through a women's bathhouse. *Feminist Theory* 8 (3): 243–62.
- Kanne, Stephen M., and Micah O. Mazurek. 2011. Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism Developmental Disorders* 41 (7): 926–37.
- Kelly, Christine. 2010. Wrestling with group identity: Disability activism and direct funding. *Disability Studies Quarterly* 30 (3–4). <http://dsq-sds.org/article/view/1279> (accessed August 25, 2014).
- . 2013. Building bridges with accessible care: Disability studies, feminist care scholarship, and beyond. *Hypatia* 28 (4): 784–800.
- Kittay, Eva Feder. 1999. *Love's labor: Essays on women, equality, and dependency*. New York: Routledge.
- . 2007. Beyond autonomy and paternalism: The caring transparent self. In *Autonomy & paternalism: Reflections on the theory and practice of health care*, ed. Thomas Nye, Yvonne Denier, and Toon Vandeveld. Leuven, Belgium: Peeters.
- . 2009a. Ideal theory bioethics and the exclusion of people with severe cognitive disabilities. In *Naturalized bioethics: Toward responsible knowing and practice*, ed. Hilde Lindemann, Marian Verweck, and Margaret Urban Walker. Cambridge, UK: Cambridge University Press.
- . 2009b. The ethics of philosophizing: Ideal theory and the exclusion of people with severe cognitive disabilities. In *Feminist ethics and social and political philosophy: Theorizing the non-ideal*, ed. Lisa Tessman. New York: Springer.
- . 2009c. The personal is philosophical is political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy* 40 (3–4): 606–27.
- . 2011. Forever small: The strange case of Ashley X. *Hypatia* 26 (3): 610–31.
- . 2013. Why we should care about global caring. In *Regulating family responsibilities*, ed. Jo Bridgeman, Heather Keating, and Craig Lind. Surrey, UK: Ashgate Publishing Limited.
- Lecavilier, Luc, Sarah Leone, and James Wiltz. 2006. The impact of behaviour problems on caregiver stress in young people with autism spectrum disorder. *Journal of Intellectual Disability Research* 50 (3): 172–83.
- Lloyd, Moya. 2007. *Judith Butler: From norms to politics*. Cambridge, UK: Polity Press.
- Mills, Charles. 2005. Ideal theory as ideology. *Hypatia* 20 (3): 165–84.
- Nussbaum, Martha. 2006. *Frontiers of justice: Disability, nationality, species membership*. Cambridge, Mass.: Harvard University Press.
- O'Neill, Onora. 1993. Justice, gender and international boundaries. In *The quality of life*, ed. Martha Nussbaum and Amartya Sen. Oxford: Clarendon Press.
- Parens, Erik. 2009. Respecting children with disabilities—and their parents. *Hastings Center Report* 39 (1): 22–23.
- Pearpoint, Jack, John O'Brien, and Marsha Forest. 2000. *PATH: Planning possible positive futures*. Toronto: Inclusion Press.

- Petterson, Tove. 2012. Conceptions of care: Altruism, feminism, and mature care. *Hypatia* 27 (2): 366–89.
- Sander-Staudt, Maureen. 2006. The unhappy marriage of care ethics and virtue ethics. *Hypatia* 21 (4): 21–39.
- Stein, Michael Ashley. 2007. Disability human rights. *California Law Review* 95 (1): 75–122.
- Tronto, Joan. 1993. *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.
- . 1995. Care as a basis for radical political judgments. *Hypatia* 10 (2): 141–49.
- . 2010. Creating caring institutions: Politics, plurality, and purpose. *Ethics and Social Welfare* 4 (2): 158–71.
- Wetherow, David, and Faye Wetherow. 2002. Community-building and commitment-building with PATH. In *Implementing person-centered planning: Voices of experience*, ed. John O'Brien and Connie L. O'Brien. Toronto, Canada: Inclusion Press.
- Whitney, Shiloh. 2011. Dependency relations: Corporeal vulnerability and norms of personhood in Hobbes and Kittay. *Hypatia* 26 (3): 554–57.