

Review of Jan Doolittle Wilson's *Becoming Disabled: Forging a Disability View of the World* (Lexington Books, 2021)

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Jan Doolittle Wilson doesn't invite as much as she compels the readers to do the uncomfortable, complicated, and necessary work of reimagining disability. Writing not only as a scholar of disability studies, but also as a disabled person, the granddaughter of a disabled woman, and the mother of a disabled child, Wilson uses an autoethnographic approach to not only get able-bodied readers to see disabled people in a new light, but also, and above all, to turn their gaze towards themselves and question their own understanding of disability. As Wilson explains, the autoethnographic approach is "defined as one in which an author draws on personal experiences to analyze and create meaning about larger social, cultural, and political phenomena" (p. 6).

After providing an overview of the main models of disability, Wilson reflects on and analyzes the experience of

her grandmother, her own disability, and especially the challenges she encounters as she mothers her autistic daughter in order to help us understand how "meanings of disability are formed in specific contexts among specific communities of people" (p. 6). In this disability view of the world, disability is not an apolitical medical condition. "Definitions of disability," according to Wilson, "are not simply the result of some universal, objective process, but the product of relations of power that are historically and socially contingent" (p. 21). This view of disability frees disabled people and their caregivers from the traditionally imposed expectation to overcome their disability; in contrast, Wilson argues in favor of social and political action to remove access barriers that create disability.

If the task of radically reconceptualizing disability seems a daunting one, Wilson makes a very compelling case, braiding her own experience with an impressive review of gender, disability, and queer history and scholarship. The book is divided into four parts: identifying disability, (re)imagining disability, locating disability, and mothering disability. Each part consists of two chapters.

In the first chapter, Wilson reviews three frameworks for defining disability. The *medical model* "depoliticizes disability by framing it as an individual problem or disease that is best approached through curing, treating, normalizing, or eliminating the "afflicted" individual" (p. 23). In the *social model*, "disability is not an individual problem, but a human variation that needs to be accommodated through the elimination of attitudinal and institutional barriers that interfere with the opportunity of all individuals to participate in society" (p. 32). This is the reason *disability identity politics*, the third disability framework Wilson reviews, defines disability as a "social location, a situated knowledge from which hegemonic and oppressive claims about disability can be questioned, critiqued and overturned" (p. 34). The rest of the book is informed by the tension between the medical model and social model of disability, as well as the framework of disability identity politics.

In "Crippling Disability Identities" (Chapter 2), Wilson points out that many theories of disability studies are informed by experiences of people with physical disabilities, while people with neurological disabilities remain discursively marginalized. Wilson draws attention to people with

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mental “illness,” a term “challenged by psychiatric survivors and mad pride proponents” who see it as a “cultural fiction invented by modern psychiatry” and instead see mental illnesses as “neurodivergences, or minds that process information and emotions in ways that differ from but are not inferior to neurotypical minds” (p. 56). Socially locating and utilizing the discomfort caused by the pejorative term “cripple,” crip theory, Wilson explains, reclaims disability identity from the assumption that “we are all disabled” arguing that, as disability scholar Lennard Davis puts it, “it is possible to say that we are all disabled by oppressions of various kinds” (qtd. in Wilson, p. 68). Thus, crip theory makes room “for chronic illness, neurological disabilities, fatness, madness, invisible disabilities, for those who seek a cure and those who do not” (p. 63). As such, crip theory has the potential to “strengthen disability activism by bringing together diverse individuals and groups committed to dismantling systems of oppression and pursuing justice for disabled people” (p. 63).

“Disability on Display” (Chapter 3) examines the resistance the disability alliance faces, beginning with media discourse and representation. As Wilson writes, “[media] serve as a tool of self-actualization, influencing the way that we think about ourselves in relationship to the images and messages we see reflected back at us on the page or screen” (p. 79). Furthermore, “for those whose interactions with disabled people are infrequent, narrow, or perfunctory, media representations are particularly knowledgeable in creating knowledge and shaping attitudes about disability” (p. 79). Dissecting the rhetoric of various movies, public health announcements, and the Jerry Lewis Muscular Dystrophy Association (MDA) Labor Day Telethon, Wilson shows how stories about disabled people authored without disabled people reinforce damaging stereotypes while promoting ableist attitudes. Wilson argues that only through the inclusion of disabled people in every aspect of the creation of their stories (including the casting of disabled actors) can an accurate representation of disability as “an unjust social condition to be remedied by political action” be achieved (p. 83).

The goal of political action is the removal of institutional barriers to access, and in “Disability and Inclusive Education” (Chapter 4), Wilson directs her attention to education, specifically addressing how classrooms fall short of true inclusivity. Drawing from her experience of mothering an autistic daughter, Wilson points to two failed models of supposedly inclusive education: placing disabled children in regular classrooms without sufficient support or, conversely, placing them in separate needs classrooms. After her daughter, Zoey, had been expelled from several private schools, she was enrolled in their neighborhood’s public school “on the assumption that she would be supported by a range of services and programs mandated by law” (p. 114). Instead, Zoey was placed in a regular classroom with no support while the school insisted on a lengthy evaluation process “despite the recommendations of our private doctors and therapists” who “had already evaluated and diagnosed

Zoey” (p. 114). As a result, Zoey’s “frustration and anxiety led to frequent, violent outbursts, which resulted in social rejection from her peers and abandonment of all education from her teacher” (p. 114). Wilson recounts Zoey’s experiences in harrowing detail. One day, for example, she went missing for an hour without anyone noticing (p. 115), while another day, she almost managed to run away from school because she was allowed to go the bathroom unsupervised by her untrained aide who was hired only after a teacher wrestled Zoey and pinned her to the floor (p. 115). This account is important because it exposes the systemic flaws of a pseudo inclusive education that “had failed on every level to accommodate” an autistic child. An education system that places a disabled child in a regular classroom “without any real support, no individualized attention to her needs, little or no training of staff, and utter failure to teach students the value of human diversity” (p. 116) is not truly inclusive.

The solution, according to Wilson, is not the special education classroom with its “limited, less rigorous curriculum” and “lower expectations that can lead to diminished academic and postsecondary opportunities, less access to non-disabled peers, and social stigma” (p. 118). Instead, Wilson challenges the readers to re-envision the inclusive classroom as a place that should accommodate not only the needs of disabled students, but also the diverse learning styles of regular students. Wilson sees the concept of the Universal Design for Learning (UDL) “as the best application of the social model of disability to educational approaches” (p. 125). UDL requires educators to think of “accommodations and adaptive technologies” not only “as useful and appropriate” for students with disabilities, but also equally helpful for “enhancing the academic performance of all students” (p. 126). In concrete terms, UDL requires educators to provide “(1) multiple methods of representation of course content, (2) multiple means for students to express what they know, (3) and multiple methods for motivating students to learn” (p. 128).

Wilson writes that her discovery of UDL made her reconsider her “fundamentally flawed” view of accommodations and transform her teaching (p. 126). The explanation of how she redesigned a course on Harry Potter to reflect the principles of UDL provides a helpful example of how to transform traditional education according to the social view of disability and achieve the promise of the verb “to educate.” If we are to rely on its literal meaning, “to educate” means not to treat students as empty or defective receptacles of information, in keeping with what Paul Freire called in the *Pedagogy of the Oppressed* the “banking” concept of education, but to recognize the knowledge that students bring to the classroom and help them contribute to the collective learning process.

I found Chapter 4 very helpful; however, it is “Borrowing within Disability” (Chapter 5) and “Making Disability Home” (Chapter 6) that provided both the most compelling reading and the most important insights. To explain her autoethnographic approach, Wilson writes, “I draw on my own distinct experiences—particularly how

parenting Zoey has led to my ‘disability becoming’—and my social location to make original knowledge claims about the social and political meanings attached to disability and the meanings and histories and lives of disabled people” (p. 6). The knowledge she contributes in Chapters 5 and 6 is embedded in her autobiography. As such, it helps readers to better understand the theoretical principles she discusses in the first two chapters.

In Chapter 5, Wilson writes movingly about her deep connection with her grandmother who experienced a serious brain injury following a car accident. She explains that watching her mother care for her grandmother helped her understand the concept of “access intimacy” or “those relationships in which disabled bodies and minds can feel safe and comfortable” and “where help and support are understood as just another form of the interdependency that characterizes all human relationships” (p. 160). The passage that I found particularly moving is the one in which young Jan’s longing for her grandmother overcomes the fear of her grandmother’s injuries and leads her to seek her grandmother’s presence and rediscover her grandmother’s love (p. 158). As she points out, after the accident, “[i]n so many ways, Grandmom remained the same, but it became increasingly apparent that the people around her had not” (p. 159).

Wilson watched with “puzzlement and eventually with hurt and anger how differently some of her friends and even family members treated” her grandmother (p. 159). Her grandmother became disabled because the world around her valued her based on “how closely she could approximate her preinjured self, and how well she could reinhabit what had become for her an often uninhabitable world” (p. 160). Furthermore, Wilson points out, her grandmother was disabled by traditional gender roles. After the accident, “she was unable to perform the activities that characterize society’s definition of ‘true womanhood’” (p. 162). This caused her “frustration and sorrow” and “shifted” her relationship with her husband (p. 162). However, through her own mother’s model of access intimacy, Wilson learned as a young girl to not allow the world to change her own view of her grandmother permanently. As a result, she was able to preserve a mutually sustaining relationship in her life.

It is this model of mutually sustaining dependency that ultimately informs Wilson’s relationship with her own autistic daughter, Zoey, described and analyzed in vivid detail in Chapter 6. In the introduction, Wilson writes that she has tried to avoid “the trappings of the ‘typical’ memoir written by parents of children with disabilities, many of which have the tendency to reify rather than challenge oppressive cultural models of disability” by emphasizing “grief over a child’s diagnosis” and framing their child’s disability “at least in part through a medicalized model” (p. 9). According to Alison Piepmeier, these memoirs “represent the child not as a person but as a problem with which the parents have to grapple” (qtd. in Wilson, p. 10).

Wilson does not flinch from describing the challenges that Zoey faced earlier on. Sharing passages from her own

diary and Zoey’s (with Zoey’s permission), Wilson describes anxieties and injuries that, I confess, made me wince. But perhaps Wilson wants us to wince, just like the essayist Nancy Mairs, whom Wilson quotes in Chapter 2 to explain to possibilities of cripple theory. According to Mairs, “People—crippled or not—wince at the word ‘cripple.’ Perhaps I want them to wince” (qtd. in Wilson, p. 62). Likewise, rather than presenting her daughter as a tragic problem her parents have to grapple with, Wilson wants us to face our own discomfort with non-normative bodies and behaviors. Instead of allowing her daughter to become disabled by our ableist reaction, she wants us to become comfortable with the diversity of human experience.

The takeaway point from Chapter 6 is not to present herself as a model mother, or to speak for Zoey’s experience, but rather to show how Zoey transformed her view of the world and human relationships. “And though I did not realize it during the early years of Zoey’s diagnoses and the beginning of my research,” Wilson writes, “I was starting to form a neurodiverse perspective” (p. 193). This perspective “understands autism as a highly variable neurological difference that is just as valid and deserving of social acceptance and equal treatment as any other neurological difference within the broad landscape of human diversity” (p. 193). This does not lead her to shun all therapy, but rather to create a list of “non-negotiable rules” by which she evaluates the “the methods, rhetoric, and attitudes of potential care providers” (p. 193). Specifically, a therapeutic approach had to:

- i) respect Zoe’s personhood;
- ii) teach Zoey skills for better coping with her environment, not focus on changing her or making her appear to be “typical”;
- iii) recognize Zoey as an expert of her experience and therefore include her in the problem-solving process;
- iv) recognize as valuable and worthy my perspective as Zoey’s mother and include me in the problem-solving process;
- v) teach me how to be a better advocate for Zoey;
- vi) give Zoey the tools to develop self-advocacy;
- vii) recommend medication only following and in conjunction with the implementation of various approaches. (p. 193)

In addition to finding this list utterly sensible, I also thought of it as a political manifesto of sorts. Just like Wilson’s refusal to keep Zoey in a public school that did not accommodate her needs at any level and her decision to homeschool Zoey until she “managed—after a lengthy and costly battle—to transfer her to the only elementary school in our district that provided a full-time, self-contained special education program run by a team of highly trained staff” (p. 116), these non-negotiable rules constitute a demand that we recognize that disability “occurs when a body enters a space that was not meant for it” and “when we assume that navigation of such spaces is an individual instead of a public responsibility” (p. 32).

Zoey’s academic success validates Wilson’s choices as a parent and an educator; however, Wilson admits that de-

spite the significant challenges her family faced, her family had access to support systems many families don't. "Disability and Constructs of Motherhood" (Chapter 7) and "Refiguring Motherhood through a Disability Lens" (Chapter 8) are, therefore, a call to action to reconsider not only disability, but also the constructs of motherhood and the support we fail to provide mothers. Many first-time mothers, myself very much included, will recognize the painful cognitive dissonance Wilson describes when her experience utterly failed to match her media-fueled fantasies of the early days of babyhood (p. 218). These fantasies seem to serve as cover for the institutional failures to provide mothers with the support they need, from the time necessary to allow a woman's labor to take its natural course, to the shortcut of recommending formula instead of breastfeeding to make the baby meet normative targets of weight gain, to the failure to provide working mothers with breastfeeding breaks.

Viewed in this light, motherhood itself is a form of becoming disabled. Just like Wilson's grandmother after the traumatic brain injury, mothers are valued based on their ability to inhabit an increasingly uninhabitable world. Mothers are "expected to neglect their own needs, desires, and even health in service of their children" and those "few, brave mothers who dare to intimate publicly that they might be deserving of a bit of self-care often face social punishment" (p. 241). In this light, self-care demands recognition of mothers' welfare as social welfare. As Wilson points out, too often "we think of equality as a goal achievable by individual will and adjustment rather than a project that requires the dismantling and reconstruction of entire economic, social, and political systems in order to make these systems work for the greatest diversity of human beings" (p. 247).

As I was reading this book, I found myself constantly reevaluating my own experiences and observations. I thought of my maternal grandfather, who lived the last four years of his life with an unidentified form of dementia, and my father who lived for a long time with undiagnosed dementia and died after experiencing a shorter, more acute, and more disabling form of it. Both had been political prisoners in Albania during communism, my father convicted of "agitation and propaganda" and condemned to five years of hard labor when he was only fifteen years old. During my first visit to Albania after his death, I visited a memorial to the politically persecuted and was struck by the information that one of the consequences of the trauma many political prisoners suffered was "loss of their mental faculties."

The relationship between trauma and disability is one that Wilson draws particular attention to when she discusses her grandmother's life, and she does not shy away from the uncomfortable questions this relationship raises. As she writes, in "refuting the ableist assumption that disability is always tragic, we should not insist that disability is never tragic" because when we do so "we discredit the experiences of those with histories of trauma and violence" (p. 149). I appreciated Wilson's observation that "disability studies seems to make

too little room for an acknowledgement of pain and feelings of loss that can follow disabling experiences" (p. 147). While it is difficult for me to not see my father's hallucinations that the police were coming to arrest him as a medical condition, I also observed as a child what happens when "a body enters a space that was meant for it" (p. 32) when I witnessed my grandmother's years-long efforts to care for her husband with little support and no accommodations. As I read the book, I came to view the Albanian institutional failure to provide any kind of support for both my grandfather and father as they became neurodivergent as a second, more insidious form of political oppression.

At the same time, I am also the mother of a four-year old child who, apart from his far-below-average weight and height is not disabled by normative statistics. As I was reading about Wilson's and Zoey's experience at her regular public school classroom where Zoey was placed with no support, I kept asking myself how I would react if my son had been one of the children who experienced Zoey's "frequent and violent outbursts" (p. 126) while she was left completely unsupported. These are not easy or comfortable questions, but one of the virtues of this book is the honesty with which Wilson tackles the complexities of disability. She gives full voice to those who take different positions, such as Christopher Reeve, the actor who was paralyzed after a horseback riding accident and faced criticism for using his star power to find a cure for spinal cord injuries instead of "eliminating disabling environment barriers" (p. 33). Wilson gives space to Reeve's claim that "I have the right to put my energies where I want them," and that "[i]n my condition, I would prefer to walk rather than to not walk" (qtd. in Wilson, p. 33). She also provides space for disability activists like Sue Robin, a nonverbal autistic author and writer of the documentary *Autism is a Word*, who describes her autism as a "constant struggle" and finds "people who are high functioning and saying society should not look for a cure offensive" (qtd. in Wilson, p. 174).

Wilson acknowledges that "positioning myself within these sometimes extremely contentious discourses is complicated and even risky" (p. 174). But it is a risk well worth taking. Although she writes of the "outrage" she feels over "how little our educational institutions, for whatever reason, truly fail to accommodate the needs of diverse learners" (p. 126), I found the tone of the book to be calm throughout, even when describing what must have been very difficult personal experiences. The book both invites and lays groundwork for more autoethnographic research and, as such, it is an important contribution to the conversation we need to have about how to make our world truly inclusive.

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