Editorial

Volume 20 Issue 2

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Abstract

In lieu of an editorial, this is a list of national and international programs that support people

with disabilities currently facing funding risks and/or threatened elimination.

Keywords: disability services

Volume 20 Issue 2

U.S. National Programs at Risk

- **Medicaid** – Health and long-term care coverage for low-income individuals with disabilities
  https://www.medicaid.gov
- **Home and Community-Based Services (HCBS)** – Supports for living independently in the community
  https://www.medicaid.gov/medicaid/home-community-based-services/index.html
- **Supplemental Security Income (SSI)** – Income support for low-income individuals with disabilities
  https://www.ssa.gov/ssi/
- **Social Security Disability Insurance (SSDI)** – Benefits for individuals with disabilities and a qualifying work history
  https://www.ssa.gov/disability/
- **Individuals with Disabilities Education Act (IDEA)** – Special education services and legal rights
  https://sites.ed.gov/idea/
- **ADA Title II** – Public sector accessibility and non-discrimination requirements
  https://www.ada.gov/ada_title_II.htm
- **Vocational Rehabilitation (VR)** – Employment training and support
  https://rsa.ed.gov/program/vocational-rehabilitation-state-grants
- **Protection & Advocacy (P&A) Network** – Legal representation and systemic advocacy
  https://www.ndrn.org
- **Administration for Community Living (ACL)** – Federal coordination of disability and aging services
  https://acl.gov
- **University Centers for Excellence in Developmental Disabilities (UCEDDs)** – Research, education, and community partnerships
  https://www.aucd.org/about-ucedds
- **Assistive Technology Act Programs** – Access to adaptive tools and technology
  https://www.at3center.net

International Programs at Risk (Impact of USAID Cuts)

- **Inclusive Education Initiatives** – Programs supporting accessible schooling and teacher training in countries such as Kenya, Nepal, and Vietnam.
- **Disability-Focused NGOs** – Organizations like Inclusive Development Partners lost more than 80% of their USAID contract funding, jeopardizing inclusive development efforts across multiple nations.
- **Community-Based Rehabilitation** – Grassroots disability services dependent on USAID funding have been reduced or halted altogether.
- **Agent Orange Rehabilitation (Vietnam)** – Programs serving children with disabilities tied to dioxin exposure were discontinued after the aid suspension.
- **Global Health Initiatives** – HIV/AIDS treatment access, maternal health services, and disability-inclusive pandemic preparedness projects funded through PEPFAR and other USAID mechanisms remain severely impacted.
- Current USAID website: https://www.usaid.gov
- For USAID's mission overview, funding model, and ongoing operations, see a previous version of the official USAID site archived via the Wayback Machine: https://web.archive.org/web/20250101/https://www.usaid.gov

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- **U.S. Representatives:** https://www.house.gov | https://www.senate.gov
- **Track policies and votes:** https://www.govtrack.us

Research Articles and Essays

On the Margins:

Examining Violent Experiences of Women and Girls with Disabilities in Uganda

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Abstract

This article explores the violence experienced by women and girls with disabilities (WGWDs) in Mayuge District, Uganda. Utilizing the social model of disability and a qualitative research approach, the study uncovers pervasive sexual violence, economic exploitation, denial of political and social rights, psychological violence, and low self-esteem faced by WGWDs. In Uganda, many WGWDs who have survived violence are economically disadvantaged and disempowered due to various factors that exacerbate their vulnerability. An inclusive rights-based approach is essential, where communities recognize the rights of marginalized WGWDs and protect them from all forms of human rights violation. Furthermore, the involvement of WGWDs in decision-making processes on issues affecting them must be promoted, regardless of the severity of their disabilities. This upholds the principle of "Nothing About Us Without Us."

Keywords: sexual violence, women, girls, disability, Uganda

On the Margins:

Examining Violent Experiences of Women and Girls with Disabilities in Uganda

This article seeks to ensure that the complexities of violence against women and girls with disabilities are appropriately understood and addressed. Women and girls with disabilities are those who have long-term physical, mental, intellectual, or sensory impairments that may hinder their full and effective participation in society on an equal basis with others per the National Policy on Disability in Uganda (Government of Uganda, 2006a), Persons with Disabilities Act (Government of Uganda, 2006b), and the National Council for Disability Act (Government of Uganda, 2003). Women and girls with disabilities face ongoing challenges such as discrimination, marginalization, social exclusion, stigmatization, and routine neglect of their social inclusion and effective participation in public life. They experience more stringent social hardships compared to men with disabilities or women without disabilities. Their difficulties are exacerbated by societal attitudes toward women and girls with disabilities.

Uganda has a supportive legal and policy framework concerning disability. The government has developed policies and enacted laws to ensure the human rights of persons

with disabilities (PWDs) and their participation in development programs. The 1995 Constitution of the Republic of Uganda prescribes affirmative action to address the imbalances affecting socially marginalized groups, including people with disabilities. It provides the basis for enacting laws and policies that address their concerns. Furthermore, it mandates fair representation of marginalized groups on all constitutional bodies and indicates that individuals with disabilities should be treated with respect and dignity.

The rights of people with disabilities are also addressed in several government acts in Uganda. For example, The Persons with Disabilities Act (Government of Uganda, 2006b) prohibits discrimination against PWDs in all forms, including those related to access to education, health, and employment. Other policies include the National Policy on the Elimination of Gender-Based Violence in Uganda and its Action Plan (Government of Uganda, 2016), the National Referral Pathway for Prevention and Response to Gender-Based Violence Cases in Uganda (Government of Uganda, 2013), and the Uganda National Gender Policy (Government of Uganda, 2007).

Despite these disability policies, studies show that women and girls with disabilities continue to experience gender-based violence more frequently than their non-disabled counterparts (United Nations, 2006b). Eighty percent of women with disabilities are victims of violence and are four times more likely to experience violence than those without disabilities (Martin et al., 2006; Valenciano, 2004). People with disabilities are at a heightened risk of domestic, economic, physical, psychological, and sexual violence due to social stigma and power imbalances in their communities.

Scholars agree that gender-based violence against girls and women with disabilities is a critically understudied topic, leaving many of their unique challenges and experiences

inadequately addressed (Hassouneh-Phillips, 2005; Curry et al., 2001; McFarlane, 2001). This lack of research and understanding has significant consequences, as it contributes to the continued vulnerability and marginalization of this group. The urgency of addressing this issue is underscored by global acknowledgments. For instance, the United Nations General Assembly meeting held on October 1, 2020, dedicated to the anniversary of the World Conference on Women conducted in Beijing in 1995, highlighted that one in three women worldwide is exposed to violence over their lifetime (United Nations, 2020), while about one in five women worldwide is a woman with a disability (UN Women, 2016).

This study interrogates the violent experiences of women and girls with disabilities in Mayuge District of Eastern Uganda. Like many others in Africa, these district women with disabilities live in a patriarchal and cultural context in which perceptions and attitudes shape public mindsets toward women and girls. This partly explains the inequalities and injustices that girls and women with disabilities continue to experience. These perceptions and attitudes not only deprive women and girls of their right to human dignity but also fosters gender-based violence and discrimination. Women and girls with disabilities experience dual layers of discrimination because of their gender and disability.

To promote the rights of women and girls with disabilities, the U.N. General Assembly adopted a resolution (A/RES/54/134) designating November 25 as the International Day for the Elimination of Violence against Women. Governments, non-governmental organizations, and civil societies are encouraged to organize events on this day to raise awareness and address this pressing issue. The campaign runs annually from November 25 to December 10 (Human Rights Day), during which various stakeholders engage in activities to increase awareness (Peterman et al., 2020).

Similarly, the International Day of Persons with Disabilities (IDPD) is observed on December 3 to promote awareness and mobilize support for the inclusion of persons with disabilities in society and development initiatives.

Method

In-depth interviews with 48 women and girls with disabilities were conducted for this study. The research participants were women between the ages of 18-45 and girls 15-17, all with long-term disabilities. Out of the 48 research participants, 30 had a physical disability, 10 had sensory impairments (visual or hearing impairment), and eight had a combination of these. The 2006 United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) recognizes these individuals as part of the disability community and acknowledges the barriers they face in participating fully in society. The interview guide for this study was created based on the lessons learned by the authors from various disability trainings.

Theoretical Framework

The social model of disability serves as a foundational theory for understanding and ensuring the rights of individuals with disabilities, including women and girls. This model views disability from a socio-political perspective, exploring how societal structures affect the participation and contributions of people with disabilities (Oliver, 2009). The Union of the Physically Impaired Against Segregation (UPIAS), an organization originating in the United Kingdom during the 1970s amidst political activism by disabled individuals, asserted that society imposes disability on people through oppressive and discriminatory institutional structures (Union of the Physically Impaired Against Segregation, 1976). Influenced by Marxist thought, scholars like Michael Oliver developed the social model, arguing that

disabilities are the result of societal restrictions rather than individual impairments (Barnes & Mercer, 2010).

The social model emphasizes the collective experience of people with disabilities, advocating for the removal of societal barriers to ensure full and equal participation. It differentiates between impairment and disability, suggesting that while impairments are biological, disabilities arise from social oppression and cultural constructs. Essentially, it asserts that societal structures disable individuals, and impairments should not limit their participation or opportunities.

To ensure the rights of women and girls with disabilities in society, an inclusive approach is essential. This involves engaging women and girls with disabilities in all phases of social and political initiatives, including planning, implementation, monitoring, and evaluation (Reiser, 2012; Ainscow, 2005). Achieving equality requires addressing the root cause of discrimination against people with disabilities. By aligning the social model of disability with inclusive participation, it becomes evident that the exclusion and mistreatment of women and girls with disabilities stem from social structures that fail to accommodate and value them. Therefore, communities must be restructured to respect and uphold the rights of people with disabilities. The social model of disability emphasizes the need for societal changes to promote inclusivity, allowing women and girls with disabilities to prosper without violations of their rights.

Data Collection

This study employed a qualitative, narrative approach to explore the experiences of violence faced by women and girls with disabilities in Uganda. Forty-eight individuals with hearing, visual, physical, or combined impairments participated in in-depth interviews. This

design allowed researchers to gather rich, personal narratives, providing a deeper understanding of the lived experiences of abuse and exploitation within their home and community environments (Clandinin & Connelly, 2000; Riessman, 2008; Webster & Mertova, 2007). The interviews were conducted in a natural setting, with researchers prioritizing participant comfort through rapport-building and flexible scheduling. All participants provided informed consent and gave permission to record their interviews. Researchers actively engaged with participants, establishing personal and professional connections while maintaining confidentiality. Probing questions were used to gain a deeper understanding of the context surrounding participants' responses.

Findings

This study explored the experiences of violence faced by women and girls with disabilities (WGWDs) in Uganda. Key findings include relationships and social challenges, economic hardship, legal barriers, and sexual violence.

Relationships and Social Challenges

While some research participants were married, cohabitation was more common, particularly among those aged 23-35. Married research participants often faced relationship challenges, and some were divorced or separated due to physical and psychological abuse from their spouses. Most girls aged 15-17 were single, with 11 being pregnant and living with parents or legal guardians. Some research participants also reported abuse by their husbands' other wives (polygamy is still practiced in some parts of Uganda) and community members. Research participants reported various forms of violence, including psychological and emotional abuse, rape, sexual harassment and assault, forced marriage, and denial of resources or opportunities. While discrimination and marginalization were widespread

experiences for WGWDs, the *degree* or *type* of vulnerability to these experiences varied based on individual factors, such as the severity of a disability, social support, and intersectionality.

Economic Hardship

Denial of resources and opportunities was frequently reported. For example, some women were restricted to growing short-term crops on small plots of land. Their husbands feared that allowing them to grow perennial crops like coffee would lead to permanent land ownership. Economic violence was also prevalent. For example, a visually impaired research participant, who sold goods and produce, described being defrauded by a customer who paid with counterfeit money, highlighting the challenges WGWDs face in economic interactions. She explained:

I am a visually impaired market woman and my companion is my daughter aged 12 years. When she is away and has gone to school, I experience challenges. One day, a male customer came and bought tomatoes, onions, and a tray of eggs from my stall. He gave me a fake note of UGX 20,000 (an equivalent of $5 in U.S. dollars). I only noticed when he had already gone. Two months later, the same customer returned and gave me a note of UGX 50,000 (an equivalent of $14 in U.S. dollars) and told me he wanted two trays of eggs. I then wanted to go to my neighbor to find change and return to him the balance. This customer insisted that he already asked my neighbors and they did not have change. He said that I should not go there but instead, I should give him the eggs and he will find change at a later time when he returns to the market. I knew that was a fake note basing on his arguments and from previous experience. I found a way of alerting two of my friends who called a police officer

from a nearby police station. When this police officer arrived, he asked me for fuel for

his car in order to take this fraudster to police. I gave some money to the police officer

and the man was arrested. I went in the same car with one of my friends and I made a

police statement. I was requested to keep reporting to police. I did this several times

once a week. I gave up after six months because it required a lot of transport.

Legal and Political Barriers

Negative community attitudes toward people with disabilities hindered their ability to

report violence and seek legal action. This aligns with research indicating that such attitudes

increase the risk of sustained injuries due to difficulties in seeking help (Dunkle et al., 2018;

Watson & Vehmas, 2020). WGWDs were often discouraged from participating in community

development and political life. For instance, a deaf research participant shared that she was

discouraged from running for a local political office exclusively because of her disability:

When I stood to compete for the position of Vice Chairperson at sub-county level,

many people in my community said that I cannot compete with an able-bodied person

who is 'normal.' Some of them had to swear before me in a crowd as many times as

possible that I cannot make it. They went to the extent of saying that they have gifts to

themselves if I ever manage to win. This really discouraged me. I feel pain not being

trusted and not accepted by my local community members. This is violation of my

political rights simply because at village level we are accorded less respect as disabled

people.

Sexual Violence

Many WGWDs experienced unwanted touching of private parts. Underreporting of

sexual violence is common due to stigma, shame, and fear. A research participant in her teens who was forced to give birth because of rape by her neighbor shared:

> One evening, as I was going to collect water from the well. Our neighbor called me. I branched to their home and sat outside. The family head gave me *chapati* [flatbread], yellow bananas and I enjoyed eating. As I stood to leave, they pulled me and locked me in one of their rooms with their *shamba* [small farm] boy. A month later, I found myself pregnant. I had to disclose the shamba boy who made me pregnant. He then said that I should not report him, he will take care of me and the child when I produce. Now the child is six months. He has not provided anything.

Research suggests that perpetrators can include family members, neighbors, and service providers, with the potential for violence leading to new disabilities (Dunkle et al., 2018). WGWDs with visual, hearing, and physical impairments were particularly vulnerable to sexual violence, facing challenges in identifying attackers and defending themselves. A visually impaired research participant described being repeatedly harassed and sexually assaulted, with her report to local authorities dismissed and trivialized.

Access to Justice and Services

Many cases of violence were handled informally at the local level, often through the local council chairperson. Barriers to movement and communication prevented further reporting. WGWDs often lacked knowledge of formal reporting procedures and community support. Negative community attitudes further hindered their ability to seek justice. Access to healthcare services was also problematic, with WGWDs reporting discriminatory treatment, long wait times, and a lack of special consideration, even when pregnant.

Awareness of Rights

While many WGWDs had knowledge of their rights, they faced significant barriers to exercising those rights. Sexual violations were commonly reported by women with visual and hearing impairments, while women with physical disabilities were vulnerable due to their limited ability to defend themselves. Overall, the study revealed that violence against WGWDs often occurs within the context of family or neighborhood relationships, encompassing emotional, psychological, physical, economic, and sexual abuse.

Discussion

This study further reveals the numerous challenges faced by women and girls with disabilities in Uganda, with significant implications for government and community programs. Existing research highlights the social problems they encounter due to cultural beliefs and a patriarchal society. As Yoosefi Lebni et al. (2020) show, women and girls with disabilities experience a multitude of difficulties, a finding that should inform the work of organizations supporting this population.

Abuse significantly lowers the self-esteem of women and girls with disabilities. Their vulnerability, stemming from their disabilities, makes them particularly susceptible to profound psychological harm from any negative experience. This finding is consistent with Curry et al. (2001), who suggest that mental health challenges such as depression, anxiety, feelings of shame, and low self-esteem often exist even before women and girls with disabilities encounter explicit discrimination based on their disability.

Negative community perceptions, attitudes, and practices toward women and girls with disabilities arise from a complex interplay of factors, including how a society is structured. These negative attitudes can contribute to or exacerbate the abuse they experience. The abuse often goes unreported within homes and institutions (including schools), and to

law enforcement agencies. Consistent with the findings of Yoosefi Lebni et al. (2020), this study also identifies cultural prejudice and patriarchy as among the key drivers of these negative perceptions.

Women and girls with disabilities are integral members of the community and deserve full protection from discrimination. The harmful belief that disability is a curse or bad omen (Nakijoba, 2020) significantly influences the discrimination this population encounters. Uganda has taken steps to ensure that women and girls with disabilities are protected from abuse, violence, and discrimination based on their disability. For example, the country ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006a) in September 2008, holding Uganda accountable for meeting the needs of this population. However, the sexual and gender-based violence women and girls with disabilities experience is heightened by limited awareness of their rights, low educational attainment, lack of resources, and dependence on others. These factors increase their risk of experiencing frequent and severe forms of sexual violence, often at the hands of neighbors and close relatives. This aligns with Bayot et al. (2006), who highlight the prevalence of violence against women and girls with disabilities within their own living environments.

Women and girls with disabilities face double discrimination because of their gender and disability. They are frequently excluded from community life – culturally, politically, socially, and economically – and are even abused by those in positions of power and protection, including individuals in government entities. Therefore, a concerted and sustained effort is crucial to protect this vulnerable population. Uganda must move beyond simply ratifying the UNCRPD. Mere ratification is insufficient; effective implementation is

paramount. The government must take decisive action, not only to translate the principles of the UNCRPD into tangible improvements in the lives of women and girls with disabilities, but also to ensure that existing national policies designed to protect this vulnerable population are fully implemented. This requires concrete measures to dismantle discriminatory practices, proactively promote awareness of their rights, empower women and girls with disabilities, and guarantee their full inclusion and safety within Ugandan society.

Conclusion

While the Ugandan government and various grassroots organizations are making efforts to promote the rights of women and girls with disabilities (WGWDs), significant gaps remain. Research indicates that WGWDs continue to experience sexual, psychological, and other forms of abuse, which severely impede their equality and the full realization of their rights.

Community attitudes present a major obstacle. Prejudice against WGWDs is widespread, but it can be challenged through collaborative initiatives involving development organizations and community members. Changing hearts and minds to foster respect for people with disabilities is essential.

Immediate action is crucial to prevent both short-term and long-term harm to WGWDs and to create safer, more inclusive communities. To effectively address these issues, funding must be allocated to evidence-based programs and the systematic collection of disability-disaggregated data, particularly at the local level. All interventions should be tailored to the specific cultural and social context of WGWDs to accurately identify their unique challenges and ensure that services are accessible to all.

The pervasive problem of violence further compounds the stigma, discrimination, and

stress (including fear and frustration) faced by WGWDs. These intersecting issues create a cascade of negative effects, impacting not only the women and girls themselves, but also their families. The Ugandan government must develop targeted strategies to mitigate these potential harms.

Recommendations

1. Comprehensive Data Collection: Regular and systematic collection of disability-disaggregated data is essential for informed decision-making on the key issues affecting WGWDs. This data should be gathered at all service delivery points and during home visits by social workers and other relevant personnel, including those at probation offices, police stations, and healthcare facilities.

2. Strategic Partnerships: Strengthened networking and collaboration among local stakeholders, particularly relevant organizations, are vital to share resources and provide comprehensive support to WGWDs.

3. Targeted Advocacy: Intensified advocacy efforts should target both individual WGWDs and the broader community to create a culture of tolerance and prevent violence. Engaging religious leaders in redefining healthy masculinity is crucial. Strict enforcement of existing laws prohibiting violence against WGWDs is necessary to reduce all forms of abuse.

4. Specialized Training: Comprehensive training for medical staff, social workers, and other key stakeholders is essential to build understanding and respect for disability and equip them to address the specialized needs of WGWDs. Service providers must be educated on the diverse experiences of their clients, including those with hearing,

visual, or speech impairments, as well as those with multiple disabilities.

5. Empowering Voices: The lived experiences of WGWDs must be heard and valued. Efforts should focus on listening to their stories, documenting their experiences, and developing solutions based on their insights. Documenting case studies and stories related to community awareness, practices, and the prevalence of violence against WGWDs should be strengthened. This should involve family members, including men, to address the patriarchal structures that contribute to discrimination.

6. Participatory Approach: The active participation of WGWDs at all levels of program development and implementation is essential. Their lived experience makes them uniquely qualified to identify challenges and propose effective solutions. This reflects the core principle of disability rights: "Nothing About Us, Without Us." The involvement of men, who are often the perpetrators of violence, is also critical.

7. Proactive Outreach and Accessibility: Service providers must actively engage WGWDs and integrate disability mainstreaming into all their activities. This will reach the many WGWDs who are often marginalized and experience disproportionately high rates of violence. Stakeholders must collaborate to ensure that service delivery points are fully accessible, with ramps, accessible restrooms, sign language interpretation, and Braille materials.

8. Investing in Evidence-Based Solutions: Funding priorities should include evidence-based research, addressing social values, norms, practices, and policies to effectively address the challenges faced by WGWDs within their families and communities. A home-based approach is highly recommended.

To conclude, by working together and prioritizing these recommendations, we can create a brighter future where WGWDs are empowered to thrive and reach their full potential without fearing abuse and violence.

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Research Articles and Essays

Divesting from the "Fake Service Dog" Narrative in Service

of a Future that Centers Care

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Author Note

Abstract

Service dog handlers face negative public judgments due to misconceptions about "fake" service dogs. This autoethnographic reflection explores how discourses about "fake service dogs" reinforce ableism, capitalism, and exclusion. It argues for shifting from policing and idealized expectations of service dogs toward a future centering care, mutual responsibility, and inclusivity for service animals and their handlers in shared public spaces.

Keywords: service dogs, ableism, disability justice, capitalism, public spaces, care ethics.

Divesting from the "Fake Service Dog" Narrative in Service

of a Future that Centers Care

Four years ago, I met the light of my life: a mostly black bundle of fur with a teddy bear face that we named Eilish. Though we didn't originally plan for Eilish to be my service dog, when the puppy trainer we were working with—who knew my disability status—suggested that Eilish might enjoy service work, we decided to try it and see what happened. I had no idea how much Eilish—both as a pet and as a team member—would change my life. She is spunky and opinionated and eager to work; she is clever and kind and bossy as all get out. The depth of relationship that she has brought into my world has healed me in ways I couldn't have dreamed before her.

Figure 1

Amy (author, service dog handler) and Eilish (service dog)
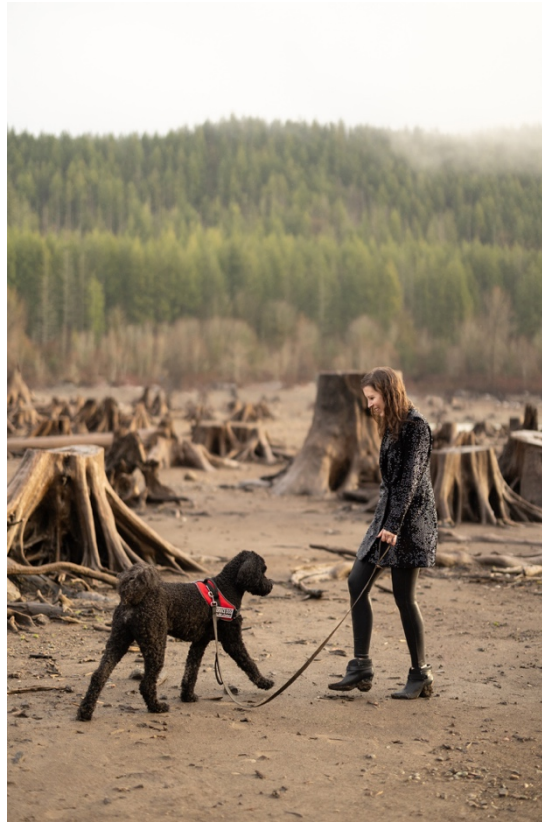
Note. Amy, a white woman with brown hair and wearing a sparkly black blazer, faces Eilish, her black Bernedoodle service dog wearing a red service harness. The two are walking toward one another in an outdoor setting with scattered tree stumps and an evergreen tree background. Photo by Claire Meyer Photography.

While Eilish's partnership has transformed my experience of public spaces, we have also become subject to ableist discourses about "fake service dogs," by the very nature of our being a service dog/handler team out in the world. "Fake spotting" (Mills, 2023), as some call it, is the policing of service dog teams by the public. Though not the focus of this piece, "fake spotting" also includes policing disabled folks' access to a variety of accommodations—for example, questioning whether someone is "disabled enough" to "deserve" a particular accommodation (Mills, 2017; Wendell, 2001).[1] "Spotting fake service dogs" takes the form of accusations ("that's not a real service dog"); declarations of disgust ("you know how I hate, I detest fake service dogs" (Cabral, 2022)); insider questions or statements ("but *we* know…");

or "simple" observations ("I saw…").

Fake spotting can be overt or implied. For example, in a recent interview on *The Bitey End of the Dog* podcast, the host, Michael Shikashio (Shikashio, 2024), interviewed Veronica Sanchez, founder of Cooperative Paws Service Dog Coach, a certificate program for professional trainers in service dog training. Sanchez began the interview defining service dogs in a way consistent with the Americans with Disabilities Act (U.S. Department of Justice, 2020), which says that a service animal is a "dog that is individually trained to do work or perform tasks for a person with a disability." Sanchez went on to distinguish service animals from emotional support animals, whose presence provides comfort to their handler (but who are not trained to perform tasks related to their handler's disability).[2] Shikashio followed with:

> Alright, so as you were talking there, you were mentioning, and it was going through my mind as well, actually, you know, the gray area there between an emotional support animal and a true service dog, and you had mentioned the task. So I'll just throw a theoretical out there for you. What if somebody's like, 'Yeah, I've got, I've got, this, my dog is a service dog.' You know, 'I have a mental condition,' or something, they say something that they have, they're not specific. 'And my dog does a chin rest on my knee when I'm having this issue.' Would that qualify as a task? Is that somebody then can say, 'Oh, this dog is a service dog,' just because it does, you know, a very baseline behavior like chin rest on my knee when I'm, uh, experiencing this.

When I heard this, my heart sunk. This quote reifies "fake service dog" narratives in a

number of ways: Shikashio says that the distinction between emotional support animals and *true* service dogs "was going through his mind as well," unprompted by Sanchez; he points out that the hypothetical service dog handler's disability is underspecified; and he asks whether a "very baseline behavior" like a chin rest "would qualify as a task." The immediate marshaling of these questions and concerns speaks to the potency of the "fake service dog" narrative.[3]

Service dogs have been called "fake" for behaviors ranging from lunging or biting in public access spaces, to panting on a plane[4], to being given a chicken nugget by their handler at McDonald's (Mills, 2023), to wagging their tail at the presence of another person (Cabral, 2022). Eilish and I have been "tsk"-ed at in national parks for being on a trail together. I have been asked if Eilish is "still in training" because she was shifting around while settled during a conference, when a fly was landing on her back repeatedly. And I have received comments about giving her a treat, as though she should not "need" that to work. Mills (2017) reports that of the 482 service dog handlers in their sample, 77.4% have had their legitimacy as a team questioned. Undoubtedly, because of the ways in which ableism intersects with and relies on white supremacy, cisheterosexism, fatphobia, ageism, classism, and every other system of oppression (Connor et al., 2016; Schalk, 2018), Black and Brown, trans, queer, fat, young, and poor folks will be more frequent and/or more forceful targets of fake-spotting, including calling service dogs fake because of the race, gender, size, age, perceived wealth, etc., of their handlers.

Mainstream public discourse about "fake" service dogs has created an environment in which I am hypervigilant and frequently downplay Eilish's and my success as a team. I feel anxious every time Eilish steps an *inch* out of not just public access standards but also the

expectations that people have of service dogs. I am hyperaware of the language I use when talking about what Eilish does for me, making sure that I use words like "task" and "trained" rather than language that suggests that Eilish's presence brings me comfort (which it does), so as to distinguish her from an emotional support animal (Price, 2017). I internally minimize the compliments we receive from members of the public, and focus instead on the questioning looks, because that feels safer to me. I *need* Eilish to be able to be in the world with me, and the world has told me that to have her with me is to conform to a particular image.

As someone who uses critical frameworks in her educational research day job (but who is not formally trained in disability studies), I am interested in what fuels "fake service dog" discourse(s). I am less interested in answers like "fake service dogs fuel fake service dog discourses" and more interested in answers that speak to the profound impact that ableism—and intersecting forms of oppression—have on the way we think, act, and feel. I approach this question as an autistic person who is drawn to complexity; as a chronically ill and disabled person invested in collective, intersectional liberation (Lakshmi Piepzna-Samarasinha, 2018); as an aspiring trainer who cares deeply about the welfare of dogs; as someone who is a member of a service dog/handler team that has been subject to these discourses; and as someone who believes that "identifying the workings of governmentality through texts … is a means to intervene in such practices to effect social change" (Price, 2011, p. 29). What follows is an autoethnographic reflection (Ellis et al., 2011) that highlights some of the resonances I've felt between "fake service dog" discourse(s) and critical frameworks that I apply to the study of science education. Here I apply these frameworks without expecting absolute theoretical coherence of myself (as if that were a thing), and

without asking myself to be comprehensive in my treatment. This is meant to be a reflection on my experience, with the support of critical frameworks.

Service Dogs as "Ideal Workers"

One of my claims is that underlying our discourse about "real" (and "fake") service dogs is the image of an ideal worker—that is, an image of a worker that ultimately serves to keep capitalism afloat, and therefore an image that is deeply ableist, white supremacist, and patriarchal.

Service dogs that "meet standards" are described as "bomb proof" (Mitchell, 2024), able to stay focused and calm in every circumstance. Veronica Sanchez (referred to above and founder of Cooperative Paws Service Dog Coach), in a podcast interview with Michael Shikashio (Shikashio, 2024), says that service dogs "are dogs that are exceptionally tolerant. These are *not* typical dogs." Likewise, in an interview with Robert Cabral (Cabral, 2022), Kristi Smith, a service dog trainer, said that service dogs should have "no reaction, no response" to another dog's presence. When asked by Cabral how important it is that a service dog has *zero* reaction to ("not even see") another dog snapping at it, or play-bowing toward it, Michele Khol, another service dog trainer and podcast guest, responded, "It's extremely important."

In many cases, service dogs are expected to pass extensive health checks and to be of "substantial size and strength," traits that are narrated as necessary for the dogs to be able "to provide effective and long-term assistance" (Parenti et al., 2015, p. 72). Dogs' capacity for service work is thought to be determined—in part or in whole, depending on whom you ask—by their biology, by their breed, and/or by their temperament. For example, Assistance Dogs International, an organization that credentials organizations for service dog training,

recently "expanded a successful breeding cooperative" whose goal is to "improv[e] the quality of all Assistance Dogs," providing more "access to a reliable and relevant puppy supply" (Assistance Dogs International, n.d.). When asked how much the "fitness" of dogs for service work is nature versus nurture in her interview with Robert Cabral, Kristi Smith responded, "I think it's about an 80/20 split, quite frankly." Service dogs are distinguished from other support animals like therapy dogs and emotional support animals by their *specialization;* they are dogs who perform specific, trained tasks for people with disabilities, not dogs whose presence simply brings comfort.[5]

An image of a dog that is able to be productive under any circumstance and in any context, a dog who is healthy, who is biologically determined as "fit" for the job, and whose work is specialized, is the image of an ideal worker.[6] This is a worker who is *ceaseless,* whose commitment to their job supersedes any other motivation. This kind of commitment is posed as necessary for the job itself, even as this imagery extends (in my view and that of others; Mills, 2023) beyond the requirements in the Americans with Disabilities Act (U.S. Department of Justice, 2020).[7]

This is the same image that has harmed disabled people, whose lives are constructed as *less valuable* under capitalism (Lakshmi Piepzna-Samarasinha, 2018; McRuer, 2006; Taussig, 2020). Our bodies do not "behave" in the ways that capitalism insists that workers' bodies should—that is, we (disabled people) obviously *have* and *are* bodies, indeed, bodies that disrupt the machinery of capitalism by calling for rest and care. In fact, Davis (2014) points out that many of us disabled folks are considered to have lives "not worth living" (p. 4), because we are thought to be outside the reach of what capitalism can make "healthy" and "beautiful."

The image of the ideal worker rarely reflects the lives and realities of disabled people, many of whom do work, would work if accommodations were made or care were offered, and/or contribute to speculative futures that disentangle us from ableism (Kafer, 2013; Schalk, 2018; Wendell, 1996). What I argue here is that the service-dog-as-ideal-worker image likewise rarely reflects the lives and realities of service dogs, service dog/handler teams, and/or the transformative possibilities of partnering with service animals. However, this image does serve to reify and reinstate the nondisabled bodymind's[8] *right to exclude*—ableism as spatiality—which I turn to next.

Ableism as Spatiality

In this section, I will draw from literature on *spatiality*—including the ways in which oppressive ideologies are spatially mediated—to unpack the role that "fake service dog" discourses, fueled by capitalist imagery of the ideal worker, play in reinstating ableism as a *right to space.*

In seminal work in whiteness studies, Ahmed (2007) describes whiteness as an *orientation*—the "here" from which the world unfolds—which shapes what is in and out of reach for particular (racialized) bodies. She argues that places and bodies are historically situated, such that our bodies inherit "the reachability of some objects" (p. 154)—that is, the extent to which things are in (or out of) our reach. We thus inherit, in our bodies and their relationship to place, a sense of how and if we can extend ourselves into space. Whiteness, Ahmed says, functions "as a form of public comfort *by allowing bodies to extend into spaces that have already taken their shape"* (p. 158), allowing such bodies to "fit in" with ease. Likewise, whiteness produces a state of dis-ease in nonwhite bodies, applying pressure when such bodies seek to extend into (white) space, and in some cases policing or punishing that

(attempted) extension into space. *Spatiality,* in this view, is a "pre-existing relation to place that guides [actors'] extension into social space based on their prior experiences in place" and their perceptions of "the normative behavioral expectations of said place" (Seawright, 2018, p.13). Price (2017), applying the lens of spatiality to disability studies, cites a "public anxiety about *bodies out of place"* (p. 4)—e.g., "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" (p. 4)—as a reflection of how ableism is mediated by space.

This sense that *whiteness* has a spatial dimension is also reflected in Harris' seminal work (1993) on whiteness as property. Harris argues that in the United States, whiteness is property, where property is conceptualized as a *right to space.* Whiteness then manifests as settled expectations of ease, access, and (by extension) the right to exclude, which are all codified in and enforced by law. Indeed, Harris argues that the *law protects whiteness,* in the same way that the law protects property rights, as reflected in a variety of Supreme Court cases throughout U.S. history. In one such case, *Regents of the University of California v. Bakke,* the defendant (Bakke), a white male, claimed that he "had been the victim of 'reverse discrimination'" (p. 1769) when he was not accepted into medical school. Evidence of discrimination, Bakke said, included that his grades and standardized test scores were higher than those of the students of color "admitted through a special admissions program" (p. 1769). The court ruled in Bakke's favor, "extending legal protection" to Bakke's expectations "of continued white privilege" (p. 1770). In her analysis, Harris points out that the admissions program "violates equal protection standards only if whites as a group can claim a vested and continuing right to compete for *one hundred percent* of the seats at the medical school, notwithstanding their undue advantage over minority candidates" (p. 1772, emphasis mine),

an advantage that was secured by "illegal oppression and segregation" (p. 1772-1773).

What I claim here is that ableism is likewise spatially mediated—that ableism is an orientation to space that extends ease and comfort to those who can approximate the image of the ideal bodymind (and *discomfort* and *out-of-placeness* to disabled folks), and that the image of the "ideal bodymind" is a form of property that is wielded by the nondisabled bodymind (or the bodymind that can approximate such) to assert their right to space. Indeed, under ableism-as-spatially-mediated, the nondisabled bodymind can assert its right to *one hundred percent* of the space, as Harris notes in the case of whiteness.

The deployment of the service-dog-as-ideal-worker via "fake service dog" discourses reflect settled expectations of the right to exclude and the right to feel at ease. When someone implies that Eilish may not belong because she is distracting them by shifting her position to remove a fly from her body, this reflects to me an expectation that the nondisabled bodymind should be free to extend itself with ease into *one hundred percent of the space.* Indeed, Mills (2023) points out that "many of the community-constructed (but not legal) requirements for Service Dog teams" rely on the "ableist belie[f] that [disabled people's] use of assistive technology and in turn, [their] disability, should remain as hidden as possible" (p. 13).

These discourses become even more alarming when we consider the ways in which affect is entangled with power. Ahmed (2014) argues that the *feeling* of uncomfortability (or fear) often becomes the *evidence* of danger, or of not-belonging-here. Building from Ahmed's work, Leonardo and Zembylas (2013) offer the example of what happens in the white body when a Black man is walking toward us on a poorly lit street at night. (I use "us" in the previous sentence to indicate my position as a white woman complicit in white supremacy.) Our (white) bodies have been conditioned to feel fear in response to the presence

of the Black body, and we then take that fear as *evidence* that the Black body is dangerous, *regardless of their behavior.*

We know that the presence of people who are marked as disabled often produces a state of dis-ease in the nondisabled bodymind. We (disabled people) "are constant reminders of … the inability of science and medicine to protect everyone from illness, disability, and death" (Wendell, 1996, p. 63). When my presence—or the presence of Eilish—is felt as discomfort, this discomfort can then serve as proof for our not-belonging-there. Particularly relevant to my case here are moments when the nondisabled bodymind feels itself to be in a state of dis-ease in our presence, and then funnels that dis-ease through the narrative of the "fake service dog" to justify our exclusion, on the basis of behavior that is absolutely typical in a dynamic relationship between a human and a dog, such as trying to get a fly off your back (I know I sound like a broken record, but really, this incident made an impression), or stress-panting in a new environment, or receiving treats to indicate that good work is happening.

Some final thoughts

Above I have argued that "fake service dog" discourses serve to uphold capitalism and ableism (and thus all interlocking forms of oppression), systems I would like to see challenged, in service of building something more liberatory. But if I suggest loosening the "grip" that these narratives hold, someone is inevitably going to ask me what I would propose instead, and someone else is going to ask but what about dogs-in-service-vests who bite. Here are some preliminary thoughts.

I don't like "fake service dog" discourses for all the reasons I just said: at their core, I see them as reifying capitalist imagery and ableist space-claiming. I also don't like the word

"fake" for all the harm it has done to people seeking support in the form of subsidies, accommodations, and care—all originally meant to *remediate* the impacts of white supremacy, ableism, patriarchy, and other forms of interlocking oppression. But I also recognize that service dogs are an *accommodation,* and accommodations are fundamentally about giving more access to ableist space; they are incremental changes that we can make while we also try to change the system.

What, then, would changing the system entail, in my view? One early step would be to shift the discourse from "fake-spotting" and "compliance" toward *welfare, interdependence,* and *collective care,* all values of the disability movements I have come to love (Lakshmi Piepzna-Samarasinha, 2018). In a world where these are primary lenses— where we understand our primary responsibility as taking care of one another—we would all have to acknowledge that public space is *shared space.* That would mean responsibility for me, as a service dog handler, to care about the safety and well-being of the people and dogs that Eilish and I are sharing space with. I do my best to work with Eilish so that people who are afraid of dogs can feel secure that she will not approach them without permission; that Eilish is not a bite risk to unsuspecting passersby; and that people with noise sensitivities can rely on us to manage how loud we are. Taking care of one another also gives me responsibility (with gratitude) for Eilish's well-being, scaffolding public access in a way that minimizes stress for her and cultivating conditions where she feels connected to me in our teamwork.

But a model of public access that centers care also makes the people that we share space with responsible for *caring about the safety and well-being of Eilish and me,* in a way that acknowledges the reality that ableism is spatially mediated. This care is partially

reflected in adhering to often-cited guidelines about what to do when you see a service dog in public, which is to ignore them as much as possible, and taking some responsibility for what unfolds interactionally when you don't. But it is also reflected in divesting from fake service dog discourses and adjusting our collective expectation that every service dog look and act like the "ideal worker" image that has been popularized. It does not make sense to me why, if it is appropriate for the service dog/handler team and their work together, a service dog should not be able to be carried, should not sniff the air as people pass, should not be able to sit rather than settle or stand rather than sit, should not be given permission to say hi to a person they know. I want service dog/handler teams to be free to be learners, to be able to make "mistakes," and to continue developing as a team over time, without fear of exclusion or punishment. I want service dogs' welfare to be a top priority; I want them to *enjoy* their work, for that work to center their agency as much as possible, for work to feel consistently rewarding for them—for them to be *dogs,* in a particular kind of partnership with humans.

There is much more to say about making this vision pragmatic, including how we hold predatory organizations accountable, how we collectively give trainers the freedom to dream possible futures that center care in their work with their clients without threatening their capacity to continue working, and how we open up space so that partnering with a service dog becomes accessible beyond those who are wealthy or can wait years for an organization to match them. But first we must agree that a different future is desirable, and to open up the space to dream about what that could be. I am eager to be in conversation about this.

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Footnotes

[1] For example, Mills (2023) reports that in a series of interviews with service dog handlers concerned about the pervasiveness of "fake" service dogs, "assessing whether a stranger's dog in public is a 'fake' Service Dog or not appears to be largely based on 1.) *whether the person 'appears' disabled or not* and 2.) the dog's behavior at one moment in time" (p. 9, emphasis mine). The policing of whether a person is "disabled enough" to "deserve" an accommodation is not my focus here, even if it is an important way in which ableism shapes disabled peoples' access to and experience of public spaces.

[2] To be clear, I find the distinction between service dogs and emotional support animals somewhat nonsensical. For example, Eilish is a PTSD service dog; she supports me through panic attacks via trained tasks that mimic deep pressure therapy. But Eilish's presence itself also mitigates the symptoms of PTSD for me. She offers a non-judgmental presence in spaces that I experience significant judgment; knowing she is there to support me has significantly decreased the frequency of panic attacks; and I dissociate less frequently when I have her to focus on in addition to the environment. This experience resonates with findings from studies that document the experiences of service dog handlers, who, for example, report that "untrained behaviors" (Rodriguez et al., 2020, p. 6), such as providing a calming presence, were more important than trained tasks for mitigating symptoms of PTSD.

[3] Thanks to Michael Shikashio (in a private communication) for feedback on this paragraph and for offering his support of this work.

[4] This video appears to have been removed from YouTube, where I originally saw it. In the video, a service dog handler positioned their camera to record a dog in a service vest who was sitting at their handler's feet, panting. The person recording the video interpreted the dog's panting to indicate stress (whereas I could have interpreted the dog as hot) and suggested that a real service dog would not be stressed on a plane. They panned the video down to their service dog, who was relaxing at their feet.

[5] Price (2017) offers a "careful rethinking" of this definition of a service dog through the lens of *crip spacetime,* posing questions that blur boundaries and situate the handler/service dog relationship in an ethic of care.

[6] To be clear, my point is not to debate whether ethology or evolutionary biology matter in a species whose genetic pool has been substantially manipulated through selective breeding. My point is to highlight that this way of talking about service dogs reifies imagery of an ideal worker.

[7] The ADA defines a service animal as a dog of any breed or size that is "trained to perform a task directly related to a person's disability." Under the ADA, dogs are allowed in public access spaces unless their presence "fundamentally alters the nature of the goods, services, programs, or activities provided to the public" in that space. The ADA is careful to elaborate that this is rare and gives the example of a zoo, where there may be animals that are the natural prey or predator of a dog and the dog's presence may evoke aggressive behaviors from those animals. Serving food in an establishment, for example, does not permit that place to exclude service dogs. Likewise, service dogs can be asked to leave if they are not housebroken or are not under the control of the handler—e.g., the dog is barking excessively. Nowhere does the ADA say that service dogs should "not see" other dogs, or that they need to pass particular health checks. The popular image of a service dog as "bomb proof" feels to me like a reinterpretation of the law, as is often the case when laws are implemented in a white supremacist, ableist society.

[8] I use the term "bodymind" as a challenge to a Cartesian dualistic view of the mind and body as separate entities and as a marker that ableism (and disability) spans the full bodymind space, consistent with the work of Price (2015).

Portrayals of Disabilities in Picturebooks with the Schneider Family Award

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Abstract

This study analyzed the portrayal of disabilities in picturebooks that have received the Schneider Family Award, a well-known children's literature award in the United States focused on disability representation. The purpose of the study was to conduct an intersectional analysis of these picturebooks to explore how characters are positioned across multiple categories such as disability, race/ethnicity, gender, class, age, and language. Using the Rating Scale for Quality Characterizations of Individuals with Disabilities in Children's Literature, the study analyzed all 17 picturebooks appropriate for early childhood that received the Schneider Family Award from 2004 to 2020. The analysis found that these picturebooks are commendable for their accurate and realistic portrayals of characters with disabilities and other positive aspects. Implications are provided for teachers, authors, illustrators, and selection committees for children's literature awards.

Keywords: disabilities, children's literature, picturebooks, intersectionality, diversity, social justice

Portrayals of Disabilities in Picturebooks with the Schneider Family Award

The purpose of the study was to conduct an intersectional analysis of picturebooks that received the Schneider Family Award (SFA) to explore how characters are positioned across multiple categories such as disability, race/ethnicity, gender, class, age, sexual orientation, religion, geographic location, and language (Christensen & Jensen, 2012). The SFA is the only identity-based multicultural literature award in the United States that focuses on disabilities. According to the American Library Association (2020), the awards 'honor an author or illustrator for a book that embodies an artistic expression of the disability experience for child and adolescent audiences.' However, portrayals of other aspects of the stories such as race/ethnicity, gender, and age of the characters with disabilities in the SFA picturebooks were previously not considered.

Minority characters with disabilities in Newbery Award-winning children's books are disproportionate compared to the students in public schools who receive special-education services (Leininger et al., 2010). In their analysis, White characters with disabilities were overrepresented, while Black, Hispanic, and Asian/Pacific characters with disabilities were significantly underrepresented. When racial/ethnic minorities with disabilities are not present in children's books, readers may develop a distorted view of the group, potentially contributing to double oppression against them. Additionally, a finding regarding picturebooks with the Asian/Pacific American Award for Literature showed a lack of child characters with disabilities. A comprehensive intersectional analysis of SFA picturebooks will test if they exhibit the same trend. This study aims to unpack how disability is considered in society as portrayed in picturebooks. The results can provide teachers and caregivers with a general knowledge of quality picturebooks that portray characters with disabilities.

Intersectionality and Disabilities

The concept of intersectionality was first explored in studies of feminism in the 19th century. Sojourner Truth, an enslaved black woman, highlighted this in her 1851 speech where she declared, 'I have plowed, I have planted and I have gathered into barns. And no man could head me. ... I have borne children and seen most of them sold into slavery, and when I cried out with a mother's grief, none but Jesus heard me. And ain't I a woman?' (Brah & Phoenix, 2004, p. 77). Later, hooks (1984) defined feminism as encompassing racism, classism, and imperialism. Crenshaw (1989) coined the term intersectionality in connection to Black feminism, illustrating how race and gender are intertwined in discrimination. Sullivan (2003) explained that double oppression can occur when an individual has multiple identities that subject them to discrimination. While race, gender, and socioeconomic status were the main axes of Crenshaw's (1991) original concept of intersectionality, many scholars have extended this to include other social categories such as ethnicity, nationality, disabilities, religion, language, age, and sexual orientation (e.g., Collins, 2015; Li, 2019; Morgan, 1996). These social categories are not merely combined to explain a group's experience; intersectionality is not additive but reconstitutive and entangled (Crenshaw, 1991; Kupupika, 2021).

Historically, 'people with Down syndrome, the first disability targeted for genetic detection and selective elimination in the 1960s, were at the time called Mongoloid idiots, a diagnostic category fusing racial and disability discrimination to warrant permanent institutionalization' (Garland-Thomson, 2019, xxvii). Jarman's (2013) review of *The Shape of the Eye* (Estreich, 2011) illustrates how the story of Estreich's daughter Laura, diagnosed with Down syndrome, manifests the entanglements of ethnicity and disability. In rejecting the

diagnosis, Laura's Japanese grandmother tried to protect her from the racialized stigma attached to Down syndrome as Mongoloid idiocy, which reflects a form of internalized ableism and belonging (Jarman, 2013, p. 201). Estreich's engagement with his Japanese heritage, his definition of family, and the history of Down syndrome suggests a shift from intersectionality toward disorientations and entanglements (Jarman, 2013, p. 202).

Disability Critical Race Theory (DisCrit)

Disability Critical Race Theory (DisCrit) is an interdisciplinary framework that integrates Disability Studies and Critical Race Theory to examine the intersections of race and disability and how these intersections shape experiences of oppression and resistance. DisCrit emerged as a response to the limitations of both Disability Studies and Critical Race Theory in addressing the complex ways in which race and disability intersect (Annamma et al., 2013). One of the central tenets of DisCrit is the recognition that racism and ableism are interconnected systems of oppression that cannot be fully understood in isolation. DisCrit scholars argue that both race and disability are socially constructed categories used to maintain power structures and justify social hierarchies (Annamma et al., 2016). By focusing on the lived experiences of individuals at these intersections, DisCrit provides a nuanced analysis of how social, cultural, and institutional practices contribute to the marginalization of disabled people of color. A key contribution of DisCrit is its emphasis on counter-narratives. Counter-narratives are stories that challenge dominant discourses and offer alternative perspectives on the experiences of marginalized groups. DisCrit values the voices of disabled people of color, who have historically been excluded from mainstream narratives, and highlights their agency in resisting and challenging oppressive systems (Annamma et al., 2018). This focus on counter-narratives aligns with broader efforts in Critical Race Theory to

foreground the experiences and voices of people of color as a means of challenging and transforming oppressive structures.

DisCrit also critiques the additive approach to intersectionality, which treats various social identities as separate and independent variables that can be simply added together. Instead, DisCrit advocates for a more integrated and holistic understanding of intersectionality that recognizes the interdependent and mutually constitutive nature of social identities (Goethals et al., 2015). This approach allows for a more comprehensive analysis of how multiple forms of oppression intersect and interact in complex and dynamic ways.

By applying a DisCrit lens to the analysis of picturebooks with the Schneider Family Award, this study aims to uncover how these books represent the experiences of disabled people of color and how they challenge or reinforce dominant narratives about disability and race. By examining the intersectional portrayals of disability in children's literature, this research contributes to a deeper understanding of the ways in which literature can serve as a tool for both oppression and liberation.

Feminist-of-Color Disability Studies

In addition to DisCrit, this study is informed by Schalk and Kim's (2020) feminist-of-color disability studies, which build upon Garland-Thomson's (2002) work. While early feminist disability studies recognized the need to engage with race, the field was predominantly composed of White women, with women scholars of color underrepresented (Bell, 2006). This lack of diversity hindered racial analysis within the field (Schalk & Kim, 2020). Feminist-of-color disability studies analyze the intersections of disability, race, and gender, using disability studies as a lens to examine the intersecting systems of ableism, heteropatriarchy, white supremacy, and capitalist violence, particularly as they assign value

or lack thereof to certain bodyminds (Schalk & Kim, 2020, p. 38). Avoiding identitarian approaches, feminist-of-color disability studies consider disability as a relationship to power rather than a fixed identity (Schalk & Kim, 2020, p. 38).

Influenced by crip theorists, feminist-of-color disability studies focus on the ableist social system that disables people, aligning with overlapping systems of domination based on race, gender, class, and sexuality. These systems tend to pathologize the bodyminds of people of color, women, and trans, nonbinary, and gender-nonconforming individuals, especially when such individuals are not legally, medically, or socially recognized as disabled (Schalk & Kim, 2020, p. 41). The pathologizing and oppressive ableist discourses are fundamental to the operation of racism, sexism, and classism. Therefore, feminist-of-color disability studies challenge the ideological operations of identity-based oppressive mechanisms such as ableism, racism, sexism, and classism.

Disability can be challenging to define because it is not an object but a social process (Davis, 1995, p. 2) and a relational phenomenon (Jarman, 2013, p. 195). As Garland-Thomson (2019) wrote, 'we wonder whether stuttering, depression, anxiety, chronic pain, or disfigurement are legitimate disabilities, alternately claiming and denying the category' (p. xxvi). To understand disability, we need to dissect the concept of the norm and the construction of normalcy rather than focusing on disability itself, similar to how scholarship on race shifted focus to whiteness and intersectionality rather than solely on people of color (Davis, 1995). With a nonnormative positivist perspective, Mitchell and Snyder (2015) argue that there is a great need for an ethical methodology from which disabled people can articulate how their lives bring something new into the world that may otherwise go unrecognized (p. 6). They suggest that the focus of current disability studies and global

disability rights movements on advocating for people with disabilities to pursue their lives much as able-bodied people do, in order to prove worthy of acceptance and as recipients of equality of treatment, can corroborate the unchallenged desirability of normative lives (p. 6).

In *About Us: Essays from the Disability Series of the New York Times*, edited by Catapano and Garland-Thomson (2019), Garland-Thomson emphasizes the significance of disabled people's own voices. Contrasted with rampant deficit views about people with disabilities, the authors of the essays in the book emphasize and detail the benefits, even pleasures, of living with disabilities as people with disabilities (p. xxviii). Bérubé (1998, 2016a), who wrote about the early years through adulthood of his son Jamie with Down syndrome, has challenged normalcy by examining disability rights, abortion, prenatal testing, and educational policy. Bérubé (2016b) also highlights the significance of disabled people's own voices. He states that intellectually disabled narrative opens a window onto a reimagining of the parameters of narrative. He also suggests intellectually disabled self-consciousness opens a window onto a reinterpretation of self-consciousness (p. 160).

Problems of Identity-based Multicultural Book Awards

It is acknowledged that identity-based multicultural book awards, such as the Schneider Family Award, face challenges. Committees for awards like the Coretta Scott King Award, the Pura Belpré Award, the Asian Pacific American Award for Literature, the American Indian Youth Literature Award, the Lambda Literary Award, and the Schneider Family Award work diligently to increase representation of minoritized and disenfranchised identities in U.S. literature. However, as Cummins (2016) points out, their efforts have not been as effective as expected:

Judges on existing identity-based multicultural book award committees are consciously striving for social justice. They believe strongly that the work they do is critically important for the identity groups on whose behalf they do it. They are right, in a theoretical sense, but what we have seen is that they have not been able to do the "world-changing" that Wiegman sees as the goal of identity studies insofar as the publication of books featuring protagonists of color has not changed since Nancy Larrick's call 50 years ago. (Cummins, 2016, p. 101)

Cummins (2016) discussed findings from a large-scale study conducted by the Cooperative Children's Book Center, noting the decreased number of books with African-American characters since 2008. One possible explanation, according to Cummins, is that primary awards like the Newbery and the Caldecott Awards, which ostensibly have nothing to do with identity, are rooted in a white male-dominated culture. The vague selection criteria that Newbery judges must follow, without an understanding of intersectionality or consciousness of implicit biases, often result in support for the interests of the publishing industry (Bittner & Superle, 2016). Furthermore, the criteria for selecting Newbery Award jurors are nebulous, only specifying that the chairperson appoints six committee members without detailing their personal or professional backgrounds. This contrasts with the more specified criteria of identity-based multicultural book awards, such as the Stonewall Award, which requires a balance of sexuality/gender among committee members (Bittner & Superle, 2016).

The publishing industry tends to produce lucrative crowd-pleasers that represent hegemonic interests, often lacking or stereotyping minoritized identities (So & Wezerek, 2020). The Newbery Medal frequently faces criticism for its lack of diversity in gender, class,

and race among its winners, reflecting broader issues in the publishing industry (Bittner & Superle, 2016, p. 73).

As primary awards remain impenetrable, authors with minoritized identities often focus on meeting the selection criteria of identity-based multicultural book awards, unable to pursue the so-called excellence emphasized by larger awards (Bittner & Superle, 2016). Jurors of primary awards tend to overlook authors' diverse backgrounds, while identity-based multicultural book awards can sometimes serve as a refuge for authors excluded from the primary selection process (Cummins, 2016). This situation creates an unreasonable dichotomy between aesthetics and ideology, exacerbating the divide between primary book awards and identity-based, multicultural, social-justice-focused awards (Bittner & Superle, 2016).

Children's Literature Research about Disability Portrayals in Picturebooks

There is a significant gap in the literature on the portrayal of children with disabilities in picturebooks. In a milestone study, Dyches and colleagues (2006) analyzed portrayals of disabilities in Caldecott picturebooks, an award based on quality illustrations. They found that these picturebooks exhibited far fewer characters with disabilities than the actual number in American schools. Characters with disabilities appeared in only 4% of the Caldecott books, whereas 12% of students in public schools had a disability during the year of their analysis. The researchers also noted that the types of disabilities represented were disproportionate to those found in the general student population. While specific learning disabilities, intellectual disabilities, and speech/language impairments are most common in U.S. public-school classrooms, the disabilities in the Caldecott books included orthopedic impairments, autism, intellectual disabilities, and visual impairments. In one case, an

intellectual disability was unrealistically portrayed, as simple-mindedness was cured magically at the end of *The Fool of the World and the Flying Ship*, retold by Arthur Ransome and illustrated by Uri Shulevitz. Only two books, *Crow Boy* by Taro Yashima (1955) and *Tibet: Through the Red Box* by Peter Sís (1998), featured child characters with disabilities. Consequently, picturebooks offer little guidance to typically developing young children in understanding how to interact with their peers with disabilities. Another notable finding was the questionable accuracy of some portrayals, such as the prince's blindness being cured by Rapunzel's tears in the Brothers' Grimm *Rapunzel*, adapted and illustrated by Paul Zelinsky. This fairytale depiction diverges from scientific understanding of blindness.

A recent study by Martinez and colleagues (2016) analyzed characters in 111 Caldecott picturebooks over 25 years, from 1990 to 2015. They found only 12% of main characters had a physical disability, one had an emotional disability, and none had a cognitive disability. Regarding racial identity, they found only one LatinX character with an orthopedic impairment, in *Viva Frida*.

There is a lack of scholarly studies on picture books with the Schneider Family Book Award. Curwood's (2013) article, the only one dealing with books that received the Schneider Family Book Award, analyzed three chapter books for young adults to examine constructions of normalcy and disabilities. Curwood recommended *Jerk, California* (Friesen, 2008), *Marcelo in the Real World* (Stork, 2009), and *Five Flavors of Dumb* (John, 2010) for critical discourse analysis. This contrasts with other Schneider Family Book Award recipients that did not centralize disability, such as *Waiting for Normal* (Connor, 2008), where the protagonist's dyslexia was not a key element of the story (Curwood, 2013). According to Curwood, "it is important that students read young adult literature where disabilities are not

sensationalized or over-emphasized; these works do not generally lend themselves as well to critical discourse analysis" (2013, p. 26). This approach can also be applied to analyzing picture books with the Schneider Family Book Award.

Unlike chapter books, picturebooks create meaning through a complex process where illustrations and narrative work synergistically to convey the author's content (Nodelman, 1988; Causarano, 2021, p. 32). The literature review suggests that an intersectional analysis of Schneider Family Award picturebooks, focusing on disability portrayals and related intersectional aspects, would significantly contribute to the literature. Additionally, analyzing the subtypes of disabilities portrayed in these picturebooks could add valuable insights to the field.

Methods

This study employs a systematic content analysis combined with an interpretive approach inspired by Disability Critical Race Theory (DisCrit). The aim is to analyze how disabilities are portrayed in picturebooks that have received the Schneider Family Award, focusing on intersectional aspects such as race, ethnicity, gender, and other social categories. This section details the research design, data collection, analytical procedures, and the alignment with the theoretical frameworks of intersectionality and DisCrit.

Research Design

The study was designed to provide an in-depth qualitative analysis of the portrayal of disabilities in children's literature, specifically within picturebooks awarded the Schneider Family Award. By integrating qualitative content analysis with an interpretive approach, the research seeks to uncover the nuanced ways in which disabilities and intersecting identities are represented. This design is informed by the principles of DisCrit, which emphasize the

interconnectedness of race and disability and the importance of counter-narratives.

Data Collection

The data set includes all 18 picturebooks that received the SFA from 2004 to 2020. These books were selected because the SFA specifically honors children's literature that portrays the disability experience. The data collection process involved several steps to ensure the appropriateness and completeness of the sample.

Selection Criteria and Screening

To address the primary research question—How are disabilities portrayed in the picturebooks with the Schneider Family Award?—the study included the entire collection of SFA picturebooks from 2004 to 2020. Initially, the complete list of SFA-winning picturebooks was obtained from the American Library Association website. Each book was then assessed for developmental appropriateness for early childhood (kindergarten level or younger) based on Lexile levels, professional judgment, and recommendations from online resources such as Scholastic Book Wizard. If any of these books were found to be developmentally inappropriate for this age group, they were excluded from further analysis, thereby limiting the study to picturebooks that were appropriate for general early childhood (preK-2nd grade) education in the U.S. In the end, only "Silent Days, Silent Dreams" by Allen Say was excluded because its Lexile Level is 790L, targeting children older than grade 3. Therefore, a total of 17 picturebooks were used in the systematic analysis for disability portrayals and intersectionality.

Data Extraction

Both the textual content and illustrations of each book were systematically extracted and documented. This process involved creating detailed notes on key narrative elements, character descriptions, dialogues, and significant visual representations that depict disabilities and intersecting identities. The comprehensive documentation ensured that both the textual and visual dimensions of the books were thoroughly analyzed.

Analytical Framework

The analytical framework for this study is deeply rooted in DisCrit and intersectionality theories, guiding the examination of how disabilities are portrayed in the SFA picturebooks. The analysis is structured around three central research questions:

1. How are disabilities portrayed in the Schneider Family Award picturebooks?

2. How do these portrayals intersect with race, gender, and other identities?

3. How do the narratives align with or challenge dominant societal discourses about disability and race?

Analytical Procedures

The analysis proceeded in several meticulously planned phases.

Coding and Categorization

Each book was read multiple times to identify and code instances of disability portrayal, character interactions, and narrative context. The coding process was informed by the Rating Scale for Quality Characterizations of Individuals with Disabilities in Children's Literature (Dyches & Prater, 2000; adapted by Pehrson, 2011). This instrument evaluates various dimensions such as personal portrayals, social interactions, sibling relationships,

exemplary practices, and the impact of disability on the plot and setting. The coding process involved an iterative review to refine categories and ensure consistency.

Intersectional Analysis

An intersectional analysis was conducted to examine how the characters' identities intersect across race/ethnicity, gender, class, age, sexual orientation, religion, geographic location, and language. This phase utilized critical multicultural-analysis approaches (Botelho & Rudman, 2009; Short, 2017) to explore aspects such as focalization (who gets to speak and whose story is told), social status (who has power), story closure (fixed or open endings), representational issues, power relations, and potential inequalities. The integration of DisCrit principles was pivotal during this stage, emphasizing the importance of counter-narratives and the social construction of disability and race within the picturebooks. This involved identifying and analyzing narratives that resisted or reinforced dominant societal discourses, with a particular focus on how these books portrayed the experiences and voices of disabled people of color (Annamma et al., 2018).

Application of DisCrit Framework

Applying the DisCrit framework allowed for a critical examination of how the intersectionality of race and disability is represented in the picturebooks. DisCrit emphasizes the interconnectedness of racism and ableism and critiques traditional narratives that marginalize disabled people of color. By focusing on counter-narratives, DisCrit provides a lens through which to analyze how the picturebooks challenge or reinforce dominant societal norms (Annamma et al., 2016; Annamma, Ferri, & Connor, 2018). The analysis sought to uncover the extent to which these books provide a platform for the voices of disabled individuals, particularly those from marginalized racial and ethnic backgrounds.

Triangulation and Debriefing

To ensure reliability and validity, the analysis included regular debriefing sessions with colleagues knowledgeable in DisCrit and intersectionality theories. These sessions involved discussing the coding process, refining categories, and addressing any discrepancies. Analytical triangulation was employed, which involved using multiple perspectives to interpret the data and reach a saturation point where no new themes emerged. This process helped to enhance the credibility and trustworthiness of the findings.

Contextualization and Interpretation

The contextualization of the findings was grounded in a comprehensive review of relevant literature, including DisCrit and intersectionality. This study acknowledges the limitations of existing children's literature in representing diverse identities and seeks to highlight both the strengths and gaps in the SFA-winning picturebooks. The interpretive approach facilitated a nuanced understanding of the portrayals, considering not just the presence of disabilities but the quality and context of these portrayals. This aligns with the principles of DisCrit, which emphasize the importance of counter-narratives and the interconnectedness of race and disability. The findings were interpreted in light of the broader social and cultural contexts, considering how the representations in the picturebooks reflect or challenge prevailing societal norms and attitudes towards disability and race.

Example of Integrated Analysis and Interpretation

Analysis Section: Social Interactions

In examining the social interactions of characters with disabilities, it is evident that these interactions are often portrayed in a positive and reciprocal manner. For instance, in "Dad, Jackie, and Me," the protagonist's relationship with his deaf father highlights the shared

experiences and mutual respect between them. This aligns with DisCrit's emphasis on counter-narratives, which challenge dominant stereotypes by presenting disabled individuals as active and valued members of their communities (Annamma et al., 2018). Similarly, "Piano Starts Here: The Young Art Tatum" portrays the protagonist's social contributions through his musical talent, promoting respect and admiration for his abilities. This depiction supports Goethals et al.'s (2015) argument that social identities are interdependent and must be understood in relation to one another. Tatum's story not only highlights his disability but also his racial identity as a Black musician, offering a holistic view of his character.

Summary of Key Findings

The analysis revealed that while the SFA picturebooks generally portray disabilities in a positive light, there are notable disparities in the representation of different disability types and intersectional identities. The findings highlight the need for more diverse and nuanced portrayals that reflect the complexity of lived experiences at the intersections of race, disability, and other social categories.

Findings: Disability Portrayal in Picturebooks with the Schneider Family Awards

The Schneider Family Awards recognize outstanding books that embody an artistic expression of the disability experience for child and adolescent audiences. This study analyzed 17 picturebooks appropriate for PreK-2nd grade that received this award, examining the portrayal of characters with disabilities across various dimensions. Each book offers unique insights into the lives of individuals with disabilities, using creative storytelling and vivid illustrations to convey their experiences. The findings highlight both strengths and areas for improvement in these representations, providing a comprehensive overview of how

disabilities are depicted in children's literature, and exploring the implications for intersectionality, bias, and representation.

The SFA picturebooks, while providing realistic and positive portrayals of disabilities, still reflect broader societal trends in the representation of gender and race. The overrepresentation of male characters and certain disability types, along with the underrepresentation of Latinx characters, highlights ongoing issues in children's literature. These disparities can influence young readers' perceptions and contribute to a limited understanding of the diverse experiences of children with disabilities. In addition to the disparities in disability types and racial/ethnic identities, the point of view in these picturebooks often comes from an omniscient third person or an adult looking back on childhood. Four of the picturebooks (23.5%) described the characters with disabilities from the protagonists' point of view, providing a more intimate and authentic portrayal of their experiences. The illustrations in the SFA picturebooks generally enhance the realistic portrayal of disabilities. They effectively depict the characteristics of disabilities, sometimes using artistic or metaphorical means to convey the experiences of the characters. For instance, the illustrations in "Six Dots" use different color schemes to represent the vision and imagination of Louis Braille, adding depth to the narrative.

Realistic Portrayals and Character Development

The analysis of the 17 picturebooks with the Schneider Family Award reveals that the portrayal of characters with disabilities is generally realistic, capturing various attributes and challenges accurately. For example, in "A Friend for Henry," Henry's characteristics of ASD are described with precision in the classroom setting, highlighting his need for order and his difficulties with social interactions. This book sensitively explores Henry's world, detailing

how he navigates his daily routines and the challenges he faces in trying to make friends. The nuanced depiction of Henry's emotions and the ways he finds comfort in routines is both enlightening and empathetic, offering a valuable perspective on the experiences of children with ASD.

Similarly, "Back to Front and Upside Down" portrays Stan, whose struggles with writing letters realistically reflect dysgraphia or dyslexia, though not explicitly labeled. The story poignantly depicts Stan's frustration and perseverance, providing an accessible entry point for young readers to understand learning disabilities. Stan's journey of overcoming his difficulties with the support of his teacher and friends highlights the importance of patience and encouragement in learning environments, showcasing how educational support can impact children with learning disabilities.

Similarly, "A Friend for Henry" does not explicitly label Henry as having Autism Spectrum Disorder (ASD), but it realistically describes his need for routine and order in the classroom. Henry arranges the carpet squares for reading time perfectly, only to become distressed when a classmate disrupts his arrangement. This portrayal highlights Henry's characteristics of ASD, such as his literal interpretation of facts and discomfort with rule-breaking, providing an authentic depiction of his daily experiences without reducing him to his disability alone.

In "Emmanuel's Dream," Emmanuel, born with only one strong leg, is depicted as a determined and resourceful character who supports his family financially. The book emphasizes his abilities and resilience, countering any notion of pity and instead highlighting his strength and resourcefulness. His story, where he undertakes a long-distance bike ride to

raise awareness for disabilities, demonstrates his self-determination and ability to overcome economic hardships.

Louis Braille's innovation and perseverance are depicted with depth in "Six Dots: A Story of Young Louis Braille," emphasizing his impact on the blind community. The narrative follows Louis from his early childhood through his invention of the Braille system, offering a detailed and inspiring portrait of his determination and creativity. The story vividly illustrates the challenges Louis faced and his unwavering resolve to create a tool that would transform the lives of blind individuals worldwide, highlighting the intersection of personal perseverance and societal change.

In "Kami and the Yaks," Kami's deafness is portrayed realistically, showcasing his bravery and resourcefulness in the face of adversity. Kami communicates effectively through gestures, and his deafness does not hinder him from understanding the world around him or taking decisive actions, such as rescuing a yak in distress. This story underscores the message that disabilities do not limit one's ability to make significant contributions and exhibit courage, providing a powerful narrative about overcoming barriers.

Narrative Perspective

A significant portion of the picturebooks (approximately 60%) utilized a third-person narrative perspective. This narrative choice, while providing a comprehensive view of the characters' experiences, often lacks the depth and personal insight that first-person narratives can offer. For instance, "Just Ask! Be Different, Be Brave, Be You" employs a collective first-person voice that seems more like an adult storyteller providing accurate information about disabilities rather than reflecting the children's voices. This approach can feel

somewhat detached, missing the opportunity to delve deeply into the personal experiences of the characters.

In contrast, "The Remember Balloons," narrated by a child observing his grandfather's dementia, uses a first-person perspective that provides a poignant and realistic portrayal of the impact of dementia on familial relationships. This narrative choice allows readers to connect more intimately with the emotional experiences of the characters. The metaphor of balloons representing memories is particularly effective in conveying the gradual loss of memory and its emotional impact on the family.

"Dad, Jackie, and Me" is narrated by the son, providing a personal and intimate view of their shared experiences, highlighting mutual respect and shared activities. The story intertwines the narrator's experiences with his deaf father and the historical significance of Jackie Robinson's entry into Major League Baseball, adding layers of racial and disability representation. This narrative approach brings a rich, personal touch to the historical and familial themes explored in the book.

The first-person narration in "A Boy and a Jaguar" offers an intimate view of the protagonist's struggles with stuttering and his journey to finding his voice and advocating for jaguars, making his story more relatable and impactful. The protagonist's passion for animals and his ultimate success in advocating for jaguars, despite his speech impediment, provides a powerful example of overcoming personal challenges to achieve one's goals.

Intersectional Representation

Using a DisCrit lens reveals disparities in the types of disabilities and racial/ethnic identities represented in the SFA picturebooks compared to the actual demographics of children served by IDEA. Orthopedic impairments, deafness, and visual impairments are

overrepresented, while speech or language impairments, developmental delays, and autism are less frequent. This imbalance can perpetuate stereotypes by failing to provide young readers with a diverse range of disability experiences. For example, Kami in "Kami and the Yaks," a child with a hearing impairment, is portrayed navigating his environment and effectively communicating despite his hearing challenges. However, the absence of characters with certain disabilities like emotional disturbances or traumatic brain injuries suggests a need for more varied representations.

The intersectional representation in the SFA picturebooks was somewhat limited. The racial and ethnic representation revealed overrepresentation of African/African-American characters (28.6%) and underrepresentation of LatinX characters (7.2%). For instance, "Dad, Jackie, and Me" and "Emmanuel's Dream" prominently feature African-American protagonists with disabilities, providing visibility but also indicating a need for broader racial representation. In "Dad, Jackie, and Me," the story intertwines the narrator's experiences with his deaf father and the historical significance of Jackie Robinson's entry into Major League Baseball, adding layers of racial and disability representation. The story provides a multifaceted view of the struggles and triumphs of both the narrator's father and Jackie Robinson, highlighting the intersection of race and disability. Similarly, in "Emmanuel's Dream," Emmanuel's journey showcases his determination and resilience in the face of physical challenges, his interactions highlighting his contributions to his family and community, promoting an empowering message. The narrative details Emmanuel's activism and the societal changes he helps bring about, offering a powerful example of individual impact. Emmanuel's story is filled with instances of overcoming societal barriers and

personal limitations, demonstrating his unwavering spirit and commitment to making a difference.

Additionally, male characters with disabilities dominate the narratives (66%), reflecting broader trends in special education but highlighting a need for more female representation to avoid reinforcing gender biases. For instance, the book "Six Dots: A Story of Young Louis Braille" effectively depicts the life and achievements of Louis Braille, but the majority of the stories center around male protagonists, leaving a gap in female representation in these narratives.

The SFA picturebooks also touch on socioeconomic struggles, an important aspect of intersectionality. Emmanuel's story, for example, highlights economic challenges faced by families of children with disabilities. Born in Ghana, Emmanuel supports his family by shining shoes and selling goods, eventually gaining national recognition for his advocacy through a long-distance bike ride. This narrative underscores the intersection of disability and economic hardship, illustrating how characters with disabilities navigate and overcome these challenges.

However, immigrant experiences and linguistic identities are notably absent from the SFA picturebooks. This gap suggests an area for further development in children's literature to more comprehensively reflect the diverse realities of children with disabilities. For example, while "My Pal, Victor" is written in both English and Spanish, it fails to delve deeply into the cultural or immigrant experiences of its characters, missing an opportunity to portray a more intersectional experience.

Discussion

The existence of the Schneider Family Award (SFA) is crucial for understanding people with disabilities and making their voices heard through picturebooks. The value of this manuscript lies not in the sample size but in the impact and significance of the SFA in the context of disability representation in children's literature. As the only book award in the United States that specifically focuses on disability portrayal, the SFA holds a unique and influential position. The awarded picturebooks serve as critical texts that shape societal perceptions and educational practices regarding disabilities. Therefore, analyzing these specific books offers valuable insights into the quality and nature of disability representation, which can influence broader discussions and practices in the field of children's literature and disability studies. This focused analysis provides depth and specificity that large-scale studies may overlook, emphasizing the importance of recognizing and critically examining prestigious, impact-oriented literary awards like the SFA.

All characters with disabilities in the SFA picturebooks were protagonists, and their disabilities impacted the plots. Characters with disabilities do appear in picturebooks with other awards, such as the Caldecott (Martinez et al., 2016), Coretta Scott King, and Pura Belpré Awards. However, as these awards do not focus on disability portrayals, such characters appear infrequently and may not impact the plots. They may be tertiary characters included in illustrations using wheelchairs or canes. Compared to these awards, the SFA, which focuses on and promotes children's books with characters with disabilities, plays a unique role.

In analyzing gender representation in the picturebooks, it is essential to distinguish clearly between gender and sex categories. This study initially employed a binary approach,

which can oversimplify and restrict the understanding of gender. Considering the diversity of gender identities beyond the binary framework is crucial. Additionally, avoiding the conflation of biological sex with gender is particularly important in the context of children's literature, where representations of gender significantly shape young readers' perceptions and understanding of gender roles. Adopting a more inclusive approach to gender representation acknowledges the wide range of gender identities and their importance in children's literature.

The picturebooks with the SFA are recommended for their accurate and realistic portrayals of disabilities. In an earlier study (Dyches et al., 2006), some disability portrayals in Caldecott Award picturebooks were problematic due to unrealistic or magical cures. In the SFA picturebooks, however, this trend was not found. Additionally, the characters were generally engaged in social environments demonstrating exemplary practices. While the characters with disabilities were not deeply developed, considering the limited number of pages in picturebooks, the character development was satisfactory. The characters were credible and showed changes as the stories progressed.

Using a DisCrit (Annamma et al., 2018) approach allowed this study to critically examine if the SFA enabled the voices of people with diverse disabilities to be heard through the picturebooks. The study discovered a disparity between the types of disabilities represented in the SFA picturebooks and those prevalent among school children in the United States. According to the USDOE (2018), speech or language impairment (SLI), developmental delay, and autism were the most frequent types of disability served by IDEA Part B among children aged 3-5 years in fall 2016, while orthopedic impairment, deafness, and visual impairment were the most frequently observed disabilities among characters in the SFA picturebooks. Representations of speech or language impairment, developmental delay,

or autism were less frequent. Neither emotional disturbance nor traumatic brain injury was represented in an SFA picturebook. This situation may allow distorted views and persistent stereotypes among young children, as they cannot learn about their peers with unrepresented disabilities through picturebooks.

The study also discovered a disparity between the proportional racial/ethnic composition in the population served by IDEA and that in the SFA picturebooks. African Americans were noticeably overrepresented in the SFA picturebooks: while 12.2% of the population served by IDEA were African Americans, 28.6% of the characters with disabilities in the SFA books were African Americans. In addition, there was only one LatinX character with a disability in the SFA picturebooks. While this comprises 7.2% of the 14 characters whose race/ethnicity could be identified, the portrayal of only one LatinX character with a disability in the SFA picturebooks could create a stereotype.

The greatest disparity found was in gender representation: 66% of the characters with disabilities were male, whereas only 34% were female. This trend, however, mirrors findings from other studies, which suggest that boys are more frequently referred to special education services due to behavior patterns and the impact of gender bias on referrals (Shifrer, 2018; Wehmeyer & Schwartz, 2001). The problem lies in the underrepresentation of female students, not an overrepresentation of male students. There should be more female characters with disabilities in picturebooks with the SFA, without reducing the number of male ones.

Furthermore, the literature indicates that racial identity and language/immigration history predict disability classification in U.S. schools (Shifrer, 2018). However, among the 17 SFA picturebooks, none portrayed an immigrant child with a disability.

These disparities in disability types, racial/ethnic identities, and gender between children served by IDEA and characters in SFA picturebooks may relate to the lack of books about minority characters in English-language literature. According to So & Wezerek (2020), in an analysis of over 7,000 books published by four major publishing companies in the U.S. between 1950 and 2018, only 11% of the 2018 subsample were written by people of color. In 2018, among 3,352 books received by the Cooperative Children's Book Center (CCBC), only fifty (0.54%) were written or illustrated by people with disabilities. Narrowing this to picture books, only six (0.41%) of 1,468 picturebooks received by CCBC in 2018 were created by authors or illustrators with disabilities. The publishing industry often publishes stories conforming to stereotypes about people of color because they are more marketable. Although this study did not focus on people with disabilities, the low number of LatinX characters with disabilities in the SFA picturebooks is related to these findings. Thus, the SFA selection committee has a significantly small pool of books, particularly for racial/ethnic minority characters with disabilities.

One notable finding is the relatively high percentage of characters with disabilities during early childhood (47.1%) in the SFA picturebooks. Other analyses found that child characters with disabilities were rare in picturebooks with other children's literature awards. Considering that picturebooks comprise the majority of reading experiences for children below the third grade (Serafini & Moses, 2014), the need for realistic fiction stories that portray young children with disabilities is urgent. Children with disabilities can see themselves in these books, while children without disabilities can learn about their peers with disabilities.

Additionally, narration by a child protagonist was rarely observed in picturebooks with other awards, where the omniscient third-person point of view was more common. Among the SFA picturebooks, however, four (23.53%) featured a protagonist describing the characters with disabilities in the first person. DisCrit emphasizes the importance of allowing disabled people of color to author their own stories (Annamma et al., 2018). Educators intentionally choose first-person accounts to explore issues of social justice, as these reflections authentically capture diverse experiences (Chafel et al., 2007; Kibler, 1996). More picturebooks written in the first-person voices of people with disabilities are needed to enhance young readers' ability to relate to and appreciate them.

Implications

For Researchers

In conducting this study, it is crucial to address potential biases, including ableism and compulsory able-bodied normativity, that might influence the analysis. This work uses the terms 'people with disabilities' (PwD) and 'children with disabilities' to align with person-first language, emphasizing the individual before the disability. However, it is important to acknowledge the ongoing debate between person-first and identity-first language and its implications for representation. Additionally, a comprehensive examination of the Schneider Family Award's judging criteria and processes, including any historical changes in decision-making, is necessary. Understanding how these books are evaluated and what criteria are used to qualify or exclude them can provide valuable insights into the political and cultural dimensions of representation. This context is essential, particularly when advocating for the urgent need to improve and diversify disability portrayals in children's literature.

More scholarly works are needed to guide authors of picturebooks in appropriately representing young children with disabilities. Not only the number of characters but also the quality of their portrayal should be emphasized for future picturebooks, aiming to create more fully developed characters with disabilities and their interactions with other characters. The cultures of these children should be more richly delineated in the text and illustrations of picturebooks receiving the SFA. The analysis protocol (developed by Dyches & Prater, 2000; adapted by Pehrson, 2011) utilized in this study is suggested as a useful instrument for researchers and picturebook authors in evaluating portrayals of characters with disabilities. It measures personality, social interactions, examples of citizenship, sibling relationships, impact of the disability on the plot, impact of the setting on the disability, point of view, and illustrations.

Additionally, more scholarly works about picturebooks with the SFA, which honors children's literature with disability portrayals, are needed. Such studies of this body of books are very rare. The International Board on Books for Young People (IBBY) awards Outstanding Books for Young People with Disabilities. This collection provides researchers with another pool of picturebooks for studying disability portrayals and disability cultures.

For Authors, Illustrators, Award-Selection Committees, and Publishers

The current study recommends that the Schneider Family Award (SFA) Committee take active steps to promote picturebooks that equitably represent race and gender among characters with disabilities. To achieve this, the committee could consider including an explicit statement on their website or in their award manual about preferring characters with disabilities from underrepresented backgrounds. This statement would signal to authors,

illustrators, and publishers the importance of diversity and inclusion, encouraging the creation and recognition of books that feature a broader range of experiences and identities.

In addition to promoting diversity through award criteria, the SFA Committee could implement outreach initiatives aimed at identifying and supporting emerging authors and illustrators from diverse backgrounds. Workshops, grants, and mentorship programs could be established to nurture talent and ensure that underrepresented voices are heard in the field of children's literature. By actively seeking out and encouraging diverse creators, the SFA Committee can help to foster a more inclusive literary landscape.

This study also suggests that authors and illustrators develop more child characters with disabilities from various cultures. The current dearth of such characters creates distortions in the picturebook world, which inadvertently marginalizes these children in the real world. When children with disabilities do not see themselves represented in the books they read, it can impact their self-esteem and sense of belonging. Conversely, when typically developing children do not encounter diverse characters in literature, they miss out on opportunities to develop empathy and understanding for their peers with disabilities.

To address this issue, authors and illustrators should be encouraged to incorporate a wide range of cultural backgrounds and experiences in their portrayals of child characters with disabilities. This includes not only racial and ethnic diversity but also diversity in terms of socioeconomic status, family structures, and lived experiences. By doing so, they can create more nuanced and relatable characters that reflect the diversity of the real world.

Furthermore, publishers play a critical role in this effort by actively seeking out and promoting books that feature diverse characters with disabilities. They should prioritize stories that provide authentic and respectful representations, avoiding stereotypes and

tokenism. Publishers can also collaborate with organizations that advocate for disability rights and multicultural representation to ensure that their books meet high standards of inclusivity and accuracy.

For Teachers

Teachers strive to select picturebooks that reflect the diversity of every child, ensuring that no implicit message in the text or illustrations privileges one hegemonic race, gender, or people without disabilities. It is essential to have more mirror books for children with disabilities in early childhood classrooms in the U.S. Currently, early childhood classrooms can actively use picturebooks awarded the Schneider Family Award (SFA) as mirror books for children with disabilities and window books for children without them. These books provide valuable opportunities for all children to see themselves and others in the stories they read, fostering a sense of inclusion and empathy.

In addition to selecting diverse picturebooks, this study suggests that teachers help their young students become aware of the distortions in picturebook representations caused by the lack of people with disabilities. By understanding these gaps, children can learn to view the world through a more critical lens, recognizing and questioning misrepresentations in literature and media (Nodelman, 1999). As Nodelman (1992, 2008) has emphasized, it is concerning to let children consume literature without a critical lens, as adult intentions and ideologies are always embedded in each text. Encouraging critical thinking from a young age helps children develop the skills to analyze and challenge the underlying messages in the books they read.

Moreover, empowering children with disabilities to author their own stories in the classroom can significantly enhance the body of literature about the lived experiences of people with disabilities. When children with disabilities write and share their stories, they contribute authentic voices to the literary world, enriching it with diverse perspectives that are often underrepresented. This practice not only validates their experiences but also helps build their confidence and sense of agency.

Teachers can support this process by creating inclusive classroom environments that encourage all students to express themselves creatively. They can provide opportunities for children with disabilities to share their stories through writing, drawing, or other artistic forms. Additionally, incorporating storytelling and narrative activities into the curriculum can help children with disabilities articulate their experiences and perspectives.

By promoting diverse picturebooks, fostering critical thinking, and empowering children with disabilities to author their own stories, teachers play a crucial role in creating a more inclusive and representative literary landscape. These efforts contribute to a more equitable and understanding society, where all children can see themselves reflected in the books they read and feel valued for who they are.

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Table 1

Seventeen SFA Picture Books for Early Childhood

Book Title	Disability Type	Racial /ethnic identity /culture portrayed	Gender	Early Childhood with disabilities portrayed	Setting	Point of Views
A Friend for Henry	ASD	Asian American	M	Early Childhood	Present in USA	Third person omniscient
Just Ask!: Be Different, Be Brave, Be You	2 with ASD, 1 with intellectual disability, 1 with dyslexia, 1 with orthopedic impairment, 1 deaf, 5 other health impairment, 2 with visual impairment, 1 with speech or language impairment	Vary	7 males, 7 females	Childhood	Present in USA	First person protagonists
The Remember Balloons	Intellectual (dementia)	African American	M	Adulthood	Present in USA	First person narrator
Rescue and Jessica	Orthopedic impairment	White	F	Adulthood	Present in USA	Third person omniscient
Six Dots: A Story of Young Louis Braille	Visual impairment	French	M	Early Childhood	Past in France	First person protagonist
Emmanuel's Dream	Orthopedic impairment	African	M	Early Childhood	Present in Ghana	Third person omniscient
A Boy and a Jaguar	Speech-Language impairment	White	M	Early Childhood	Present in USA	First person protagonist
A Splash of Red	Orthopedic impairment	African American	M	Adulthood	Past in USA	Third person omniscient
Back to Front and Upside Down	Dysgraphia/Dyslexia	Animals	M	Early Childhood	Present in USA	Third person omniscient

The Pirate of Kindergarten	Visual impairment	White	F	Early Childhood	Present in USA	Third person omniscient
Django	Orthopedic impairment	Gypsi	M	Adulthood	Past in Europe	Third person omniscient
Piano Starts Here	Visual impairment	African American	M	Early Childhood	Past in USA	First person protagonist
Kami and the Yaks	Deaf	Sherpa Culture	M	Early /Older unclear	Past in Nepal	Third person omniscient
The Deaf Musicians	Deaf	Unapparent	2 Males and 1 Female	Adulthood	Present in USA	Third person omniscient
Dad, Jackie, and Me	Deaf	White	M	Adulthood	Past in USA	First person narrator
My Pal, Victor	Orthopedic impairment	LatinX	M	Early Childhood	Present in USA or Mexico	First person narrator
Looking Out for Sarah	Visual impairment	White	F	Adulthood	Present in USA	Third person omniscient

Research Articles and Essays

My Life, My Words: Postsecondary Transition Outcomes for Young Adults with Intellectual & Developmental Disabilities

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Abstract

Young adults with intellectual and developmental disabilities (IDD) struggle to integrate into their communities after postsecondary transition despite decades of policy and research initiatives, and few studies explore adult role participation outside the home from their perspectives. This study employed narrative inquiry grounded in critical disability theory to enable young adults with IDD to conceptualize community integration in their own words.

Keywords: intellectual and development disabilities, postsecondary transition, community integration

My Life, My Words: Postsecondary Transition Outcomes for Young Adults with Intellectual & Developmental Disabilities

Assuming adult roles upon leaving school is perhaps the most challenging transition in a lifetime, yet this journey is especially perilous for students who lose the support of the Individuals with Disabilities Education Act (IDEA) (Acharya et al., 2017; Newman et al., 2011). The Office of Special Education and Rehabilitative Services (OSERS, 2015) defines transition for students with disabilities as the "passage from secondary education to participating in postsecondary education, training, or both, engaging in meaningful employment, living within one's community, exercising self-determination, and contributing to society as productive citizens" (p. 1). However, with no comprehensive public policy to pick up where IDEA leaves off, families are left feeling anxious and abandoned, comparing transition to "falling off a cliff" (Franklin et al., 2019; Joly, 2015). As a result, young adults with disabilities are struggling to successfully integrate into adult roles in the community defined by OSERS such as in employment, civic engagement, socialization, participation in religions, and volunteering (Newman et al., 2011). Those with intellectual and developmental disabilities (IDD) are experiencing the greatest delays (Benson et al., 2021; Lee & Morningstar, 2019). Yet, the perspectives of such young adults are consistently omitted from community integration research about them (Jacobs et al., 2018; Lee & Morningstar; 2019). Therefore, this study empowered persons with IDD to describe community integration in the decade following postsecondary transition through multimedia narratives.

Background & Literature Review

Chang et al. (2013) define community integration as "active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role" (p. 772). When the 1975 Education for All Handicapped Children Act granting free and appropriate public education for all was reauthorized in 1990 as IDEA, it included a mandate that transition services be addressed on individual education plans (IEP) starting at age 16 in recognition of persistent struggles with community integration (United States Department of Education, 2023). However, when the decade-long National Longitudinal Study-2 (NLTS2) sponsored by the Department of Education, taking a broad view of transition that included community integration, concluded in 2009, it highlighted persistent transition deficits for young adults with disabilities despite the postsecondary transition planning mandate. For example, within a decade of transition, only 60% of young adults with disabilities enrolled in postsecondary education (PSE) as opposed to 67% of the general U.S. population; only 60% were employed as opposed to 66% of the population; and only 45% were living independently as opposed to 59% overall (Newman et al., 2011). And those labeled with significant disabilities such as autism spectrum disorder (ASD) or intellectual disability (ID) fared even worse with employment rates of only 37% for ASD and 39% for ID, while only 17% with ASD and 36% with ID were living outside the family home. There were also indicators of social isolation from the community, with only 48% of respondents with ASD and 58% with ID having recently seen friends outside the home (Newman et al., 2011). Yet obstacles to successful transition are well-documented.

Decades of transition literature has identified bureaucratic failings in the postsecondary transition process such as limited availability of information and resources to

families, underdeveloped self-advocacy and self-determination skills in adolescents with disabilities, limited stakeholder collaboration, limited family involvement in the process, siloed services that fail to coordinate, and generic training that ignores individual strengths and preferences (Franklin et al., 2019; Hirano et al., 2018; Joly, 2015; Stein et al., 2016). There is also a need for more clearly identified stakeholder roles, more effective communication channels, increased training for professionals, and incentives for cross-agency collaboration (Benson et al., 2021; Oertle et al., 2021; Plotner et al., 2020.) In turn, evidence for strategies that promote successful vocational transition is growing, emphasizing early career exploration, improved stakeholder communication, community involvement in planning, early paid work experience, and providing individualized services tailored to a student's interest (Kester et al., 2019; Oertle & O'Leary, 2017; Qian et al., 2018; Rast et al., 2020). Yet the persistent barriers have resulted in slow implementation and continued struggles to achieve competitive employment for those with complex disabilities (Lee & Morningstar, 2019; Qian et al., 2018). Postsecondary education also correlates with higher rates of competitive employment (Sannicandro et al., 2018) and there have been some successes on this front, such as the Higher Education Opportunity Act of 2008, which has helped increase PSE programs for students with ID tenfold (Baker et al., 2018; Wilczenski et al., 2017). However, successful PSE participation for those with IDD requires supports that are often absent or difficult to access such as inclusive classes, strong campus engagement, concurrent part-time employment, and collaborative engagement with community partners (Domin et al., 2020; Horn et al., 2020; Qian et al., 2018). Further, the social barriers to disclosing disability and requesting accommodations as well as the complex social and bureaucratic systems remain significant obstacles (Bell & Zamani-Gallaher, 2017; Berg et al.,

2017; Shogren et al., 2018). Yet struggles with community integration extend well beyond PSE and employment.

Critical disability studies (CDS) in particularly is grounded in calls for greater participation and inclusion for marginalized populations (Hall, 2019), and many disability studies scholars argue for measures of postsecondary transition success that includes broad views of community integration. Liasidou and Symeou (2018) argued that marketplace conceptualizations of educational outcomes reduce education to an investment and thus the educated to units of corporate profitability, often rendering persons with disabilities as nonessential. Black and Lawson (2017) similarly rejected a narrow dehumanizing focus on productivity that ignores personal priorities, while Charlton's (2000) "*Nothing About Us Without Us" slogan* remains a cornerstone of disabilities studies, scholars argue that self-actualization and not economic utility represents true freedom from oppression and thus should be our goal. But while a community integration approach is slowly seeping into transition literature, Dean et al. (2016) found that participation—as defined by widely accepted International Classification of Disability (IFC) language—was only mentioned in 88 articles within ID literature and clearly defined in six, with only three of those citing IFC language. Chang et al.'s (2013) systematic review similarly found that instruments used to measure community integration were inconsistent and failed to fully embrace participation per IFC guidance, while a systematic review by Taylor-Roberts et al. (2019) uncovered widespread psychometric scores with standardized measures of community integration. Yet not only is transition research struggling to fully define and measure community integration, but we are ignoring the most critical piece to this puzzle. A literature review by Jacobs et al, (2018) found that not only were the voices of those with IDD excluded from transition

literature in favor of other stakeholders, but few authors even bothered to justify this exclusion, clearly failing to comply with the inclusive and emancipatory mandate of CDS (Hall, 2019).

Yet calls from movements such as CDS to include these voices are slowly making inroads. Hall's (2017) qualitative study of community involvement of persons with IDD in the Midwestern United States examined community transition through employment, recreation, and leisure. The study described the internalized sting of exclusion from both vocational and social participation, paired with a desire to become more involved. Yet a preponderance of community integration literature remains quantitative, relying heavily on microanalysis of the NLTS2. Even original quantitative studies of community integration, such as that of Tint et al. (2017), rely on caregiver perspectives. Amado et al.'s 2013 literature review identified an urgent need to include the perspectives of young adults with IDD. Six years later, Lee and Morningstar (2019) found such inclusion still lacking, calling for "extending current research to provide a deeper and more descriptive understanding of community participation among young adults with severe disabilities" (p. 196). Therefore, this study employed narrative inquiry to allow this population to broadly conceptualize their community integration following postsecondary transition in their own words.

Research Methods

Narrative inquiry asserts that humans organize and explain the randomness of their lives through narratives built upon shared stock stories (Clandinin, 2016; Kim, 2016). Narrative inquirers seek *collaborators* rather than subjects to cooperatively collect and create narratives, thereby flattening traditional power dynamics where data collection and interpretation was predominately controlled by the privileged researcher (Clandinin, 2016;

Kim, 2016). Because of this collaborative empowerment, narrative inquiry has been embraced by critical disability theory (CDT)—the theoretical expression of CDS which defines disability as the confluence of contextual and personal factors rather than an individual fault (Bjornsdottir et al., 2014; Hall, 2019; Sigstad & Garrels, 2017; Smith-Chandler & Swart, 2014). However, citing the need to protect vulnerable populations, researchers and institutional review boards (IRBs) have perpetuated exclusion of persons with IDD from such research by exaggerating the challenges of collaboration and underestimating their ability to comprehend the social benefits of research participation (McDonald et al., 2016; Sigstad & Garrels, 2017). Fortunately, disability studies provides a clear path forward.

Adapted Methodology

For this study, narrative inquiry was modified per adapted collaboration recommendations from disability studies and CDT. For example, St. Pierre (2015) challenged researchers to enable non-traditional speakers by embracing noise, dissonance, silences, and alternative methods of communication, while Sandahl (2018) offered visual media as a path towards inclusive research. Nind (2008) also recommended a multimedia approach for overcoming challenges for collaborating with those with IDD in a National Center for Research Methods report. Other recommendations included using simple language, restating concepts, frequently checking for understanding, allowing increased processing time, and attending to non-verbal cues (Jovchelovitch & Bauer, 2000; Nind, 2008; Sigstad & Garrels, 2017; St. Pierre, 2015).

Drawing from a different tradition, psychology literature demonstrated how superhero iconography empowers therapeutic expression (Lawrence, 2006), while narrative psychology

proved that people who develop positive story arcs exhibit greater resiliency and self-esteem (McAdams & McLean, 2013; Murray, 2003). Therefore, combining narrative inquiry and CDT-recommended multimedia approaches with culturally available stock stories and narrative psychology led to a unique method of creating narratives via comic books to provide an accessible story structure that empowers collaborators as heroes of their own journey in opposition to victimization stereotypes.

Instrument Development

Semi-structured interview scripts were developed with a clear beginning, middle, and end of the transition journey. These were based upon the adaptations noted above and holistic inquiry survey of community integration using Rosenbaum and Gorter's (2012) six participation categories derived from IFC language: *family, fun, friends, fitness, function, and future*. Next, methodological and population experts reviewed the script and made recommendations while the language was confirmed at a 5th grade level through Microsoft Word analysis.

Sampling

Setting

Participants were selected from three programs through an organization serving persons with IDD in North Florida. Confidentiality documents were signed by the researcher and agency supervisors that assisted in sampling per IRB recommendation.

Participant Selection and Sample Size

Purposeful sampling was conducted to identify attendees who:

1. Had an IDD-related diagnosis

2. Received IEP transition services

3. Exited secondary education within 10 years (ages 18-32)

4. Possessed basic speech or augmented communication ability

5. Received vocational rehabilitation services (VR)

By studying young adults within a decade of graduation, I was able to extend the study's scope beyond the oft-studied immediate aftermath of transition. Additionally, I extended the age range to 32 as persons with IDD often stay in school until the year they turn 22, as allowed under IDEA.

Recruitment and Consent

Seven participants were recruited, and all were able to provide legal consent. IRB oversight confirmed consent forms were transparent and free of coercion. Restatement of informed consent was also built into each interaction. Collaborators were monitored for hesitancy, confusion, or other signs of involuntary consent as well as signs of intentional dishonesty; however, such concerns did not arise.

Data Collection

Collaborations required five to six sessions each of around 45 minutes, with no more than two interactions scheduled in a week. Allowing participants to choose secret identities from the outset created buy-in, while reinforcing the narrative structure and concretely demonstrating the importance of confidentiality (Figure 1). Raw data was collected in the first two sessions using interview scripts, then transcribed and printed. In two to three additional sessions, the researcher and collaborators sifted through and organized raw data into narratives while selecting or creating associated images. Initially, final text was handwritten by the researcher as agreement was reached, but this proved cumbersome and

collaborator attention wandered. So the researcher began typing the text and printing it. Typing also allowed for greater on-site editing, as text was continually shared and modified with collaborators to assure their perspectives and not the language of the researcher were being captured. Collaborators contributed photographs, drawings, and magazine clippings as well as chose from stock images via internet search. Images and texts were then arranged in narrative order and pasted into comic books formed from card stock. A final member check was then performed during an additional interaction to assure narrative accuracy. All seven collaborators completed the process and expressed satisfaction with the results.

Figure 1

Covers from Two Completed Narratives
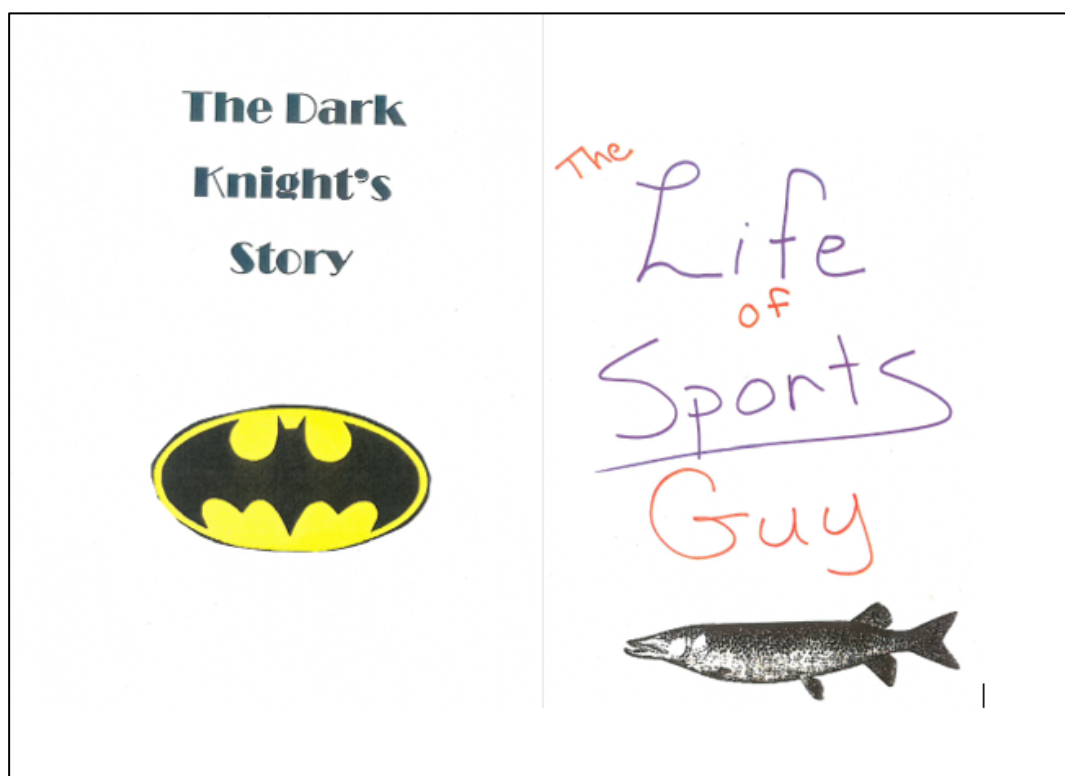
Data Analysis

Two rounds each of first cycle coding and second cycle coding were conducted per Polkinghorne's narrative analysis and analysis of narratives as modified by Kim (2016). To respect the intended communication of collaborators, only member-checked completed narratives were coded and analyzed. First cycle provisional codes derived from the literature review applied deductive reasoning to narrative text and images while open concept coding allowed for inductive analysis. In this way, data was both related to existing concepts and examined for novel expression. For second cycle narrative coding, the books were read aloud and compared, then their overarching themes were summarized into three sentences (beginning, middle, and end). Finally, pattern coding was used for triangulation of first cycle and narrative coding into categories and emergent themes. After multiple iterations of pattern analysis, four themes emerged.

Results

Demographics

Two females and five males collaborators participated, reflecting an IDD category that skews male. One male participant was a first-generation immigrant with parents hailing from Asia and Africa. All other participants were White, not Hispanic. Two collaborators fell within what was labeled the early transition period (19-24), three mid-transition (25-28), and two late transition (29-32). Two were diagnosed with ASD, one with Down syndrome, one with ADHD, and one with cerebral palsy. Other diagnoses included bipolar schizophrenia, visual impairment, and auditory impairment. Three collaborators had a history of seizure. Three lived at home with parents, three in a group home, and one lived in supported living. Two collaborators were employed part-time while four reported previous employment. One

never held paid employment. One collaborator identified as gay; five referenced heterosexual

relationships (Table 1).

Table 1

Collaborator Demographics (N=7)

Characteristic	*n*	Characteristic	*n*
Gender		Age	
Male	5	Early Transition (19-24)	2
Female	2	Mid Transition (25-28)	3
		Late Transition (29-32)	2
Sexual Identity		Living Situation	
Heterosexual	5	Independent	0
LGBTQ	1	Supported Living	1
Not Addressed	1	Group Home	3
		Parents	3
Diagnoses		Employment	
IDD	7	Full-Time	0
ASD	2	Part-Time	2
Seizures	3	Currently Unemployed	4
Cerebral Palsy	1	Never Employed	1
ADHD	1		
Bipolar Schizophrenia	1	Race/Ethnicity	
Down Syndrome	1	White	6
Hearing Impaired	1	Multinationality	1
Visually Impaired	1	(non-White)	

Narrative Themes

Happiness is a Friend: Social Support, Not Community Integration, Drives Quality of Life (QOL)

    Transition and CDS literature cite community integration indicators such as work, civic engagement, and leisure engagement as primary contributors to QOL, but community integration was not a dominant driver of QOL in these narratives. Instead, QOL was primarily expressed through human connection within and outside the home and in turn influenced how community integration was perceived. Those who felt more confident in their personal connection felt more connected to their community despite quantifiable engagement levels. For example, most narratives established initial context through recollections of

childhood friendships. Daredevil began: "When I was little, I played with Disney toys with my brother and sister [and] went to daycare and passed ball with my friends…. I was a happy child." Pudding reminisced, "When I was young …. I had friends at school and a close best friend who was like Pudding #2." Batgirl stated, "I had a best friend, and we would play outside after class," while Diana was friends with all her classmates. Despite severe early impact of his disability, Bus Rider was also a social child with many friends, and while Sports Guy was bullied in early childhood, he enjoyed playing sports with other children. By contrast, The Dark Knight was the only collaborator to lack friends, lamenting: "Nobody liked me. I wanted to make friends, but I was just a loner." Yet, like the others, he achieved childhood stability through family connections.

Batgirl stated, "What makes me unique is that I am a very happy person and that I spend big time with my family," while Daredevil declared: "What makes me special is how much I love my family." The Dark Knight focused on family memories over peer isolation, while close sibling relationships were a key to Diana's, Batgirl's, and Daredevil's identities. Both Diana and Batgirl included more pictures of their siblings than anything else, and though Pudding was bullied by his older brother, they now talk regularly. Reflecting upon a different sibling dynamic, Sports Guy accepted banishment from his house when his stepfather explained he was setting a bad example for his younger brother and sister. The friendless Dark Knight was also the only collaborator without a sibling, although extended family was critical for him as well as others.

Despite being forced into group homes, Sports Guy concluded: "I am happy knowing that so many people actually care about me—my mom, my stepdad, family, but also everybody here." A stepparent was also critical to Bus Rider: "When I was five, I met my dad

[who] taught me to do things like ride a bike and put on my socks." Grandparents were also prominent. Bus Rider's grandfather inspired his love of heavy machines by teaching him to operate farm equipment (Figure 2), while Sports Guy's grandfather brought him into his tile business during his turbulent teens. Batgirl, Diana, and Pudding also had close relationships with grandparents, while aunts, uncles, and cousins were sources of leisure and travel for Batgirl, The Dark Knight, and Sports Guy. So, while the research script was designed to focus on community integration, collaborators consistently steered their narratives toward personal connection.

Figure 2

*Bus Rider's Family Connections*
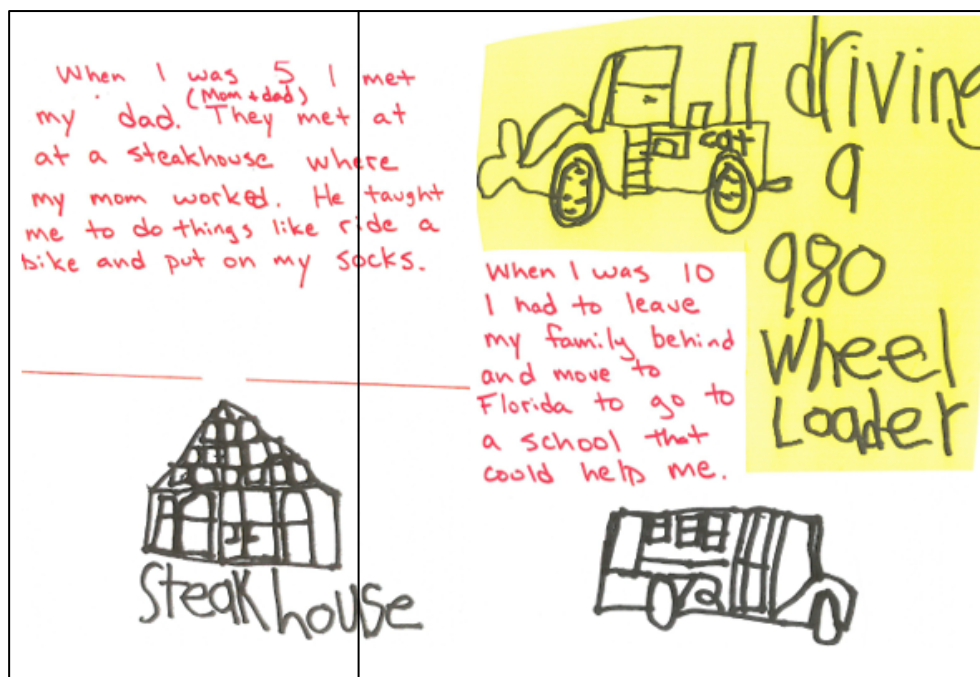
The Adolescent Earthquake: Transition Begins Earlier Than Expected

Despite stable childhoods, most collaborators encountered turbulence in early adolescence upon the transition to middle school due to increasingly complex social

relationships, emerging sexuality, and the ubiquity of bullying. Daredevil's only recollections of secondary school revolved around bullying: "There was a boy who would follow me and tease me about having a girlfriend, and teachers at school told him to stop and leave me alone, but he wouldn't" (Figure 3). Pudding similarly recalled: "I started to have more troubles in middle and high school when other kids started picking on me." And for The Dark Knight, isolation morphed into aggression:

> I was bullied a lot—mostly name calling. Because I was slow they used to call me slow and the A-word—a curse word … . The teachers said to one of the bullies: "Just stop bullying him." And they still didn't listen … so they kept doing it … anywhere I turned … I basically got bullied (Figure 3).

Diana also recalled: "In high school … I was in class with new friends who said I am stupid, I am creepy, and that I am not beautiful enough." However, teacher intervention ended her harassment, and she made new friends. But in adolescence, such external shockwaves are inseparable from internal tremors which hit collaborators particularly hard.

Figure 3

Bullying as Described by The Dark Knight & Daredevil
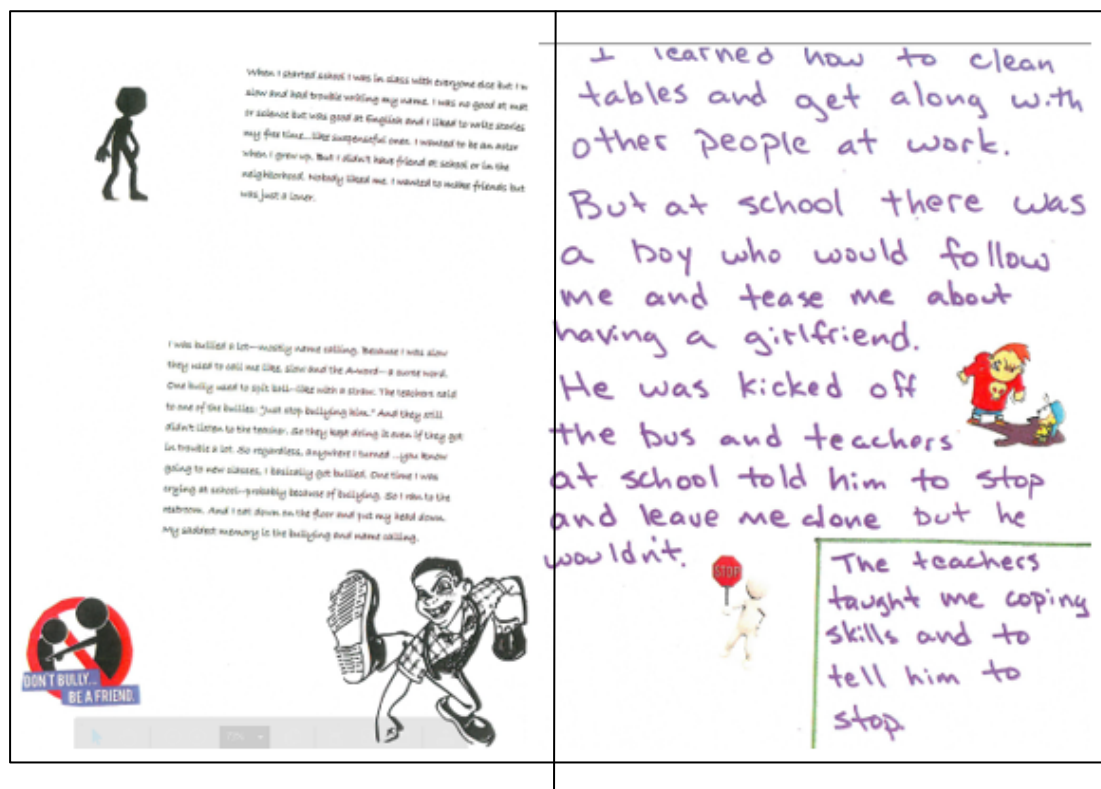
For Sports Guy, adolescence resulted in seizures and mental health issues, and things quickly spiraled out of control: "I started going in and out of the damn psych unit. This continued all through middle school and high school … . I would go in for one day and they would dope me up." He was soon kicked out of his home and has bounced around ever since. And while both Diana's and Daredevil's bullying involved emerging sexuality, Pudding identifying as gay led to such severe harassment his mother transferred him to a special

school out of state which, like Sports Guy, began a life of institution hopping. Despite the disruptive role of emerging sexuality, such issues went largely unaddressed.

Sports Guy lamented: "Nobody ever really talked to me about sex or relationships," while Pudding admitted his inability to appropriately express his sexuality led to expulsion from secondary school, an adult vocational program, and supported living. He now lives in a group home after being penalized but never educated: "I would … like to learn how to not touch inappropriately and how to start a relationship." Bus Rider maintained a successful relationship throughout his years in a specialized school, but it ended upon graduation due to a lack of transportation, and his mother restricts his ability to leave his group home out of worries over sexual contact. In some cases, however, effective institutional supports mitigated the turmoil.

Batgirl and Bus Rider escaped secondary school bullying while attending supportive institutions. Batgirl felt valued and connected through responsibilities such as helping younger children to the bus. Bus Rider attended a diagnosis-specific institution where he too felt engaged and supported, and effective intervention mitigated bullying for Diana. In contrast, teachers were unsuccessful intervening on behalf of Daredevil and The Dark Knight, leading to overwhelmingly negative secondary school experiences. Pudding's harassment was so severe he moved out of state and eventually dropped out. Sports Guy also dropped out, while The Dark Knight persevered but likened graduation to escaping to freedom. Overall, then, difficulties integrating into controlled secondary school communities foreshadowed community integration delays in young adulthood.

DisAbility Identity: I Am a Complex Person not a Disability

Although study design sought insight into how participation and community integration informed self-conceptualization, collaborator identities emerged not from how their communities embraced and integrated them. Rather, they emerged from how they perceived their own strengths and interests as well as what they could contribute, if allowed. When asked what makes them special, Daredevil, Batgirl, and Diana all referred to loving their family while for Pudding it was being a good and honest friend. Sports Guy proudly described being a recovered alcoholic, and Bus Rider declared: "I will always be the strong man that I know I can be. I'm not going to let anything stop me." Despite his turbulent adolescence, Pudding formed his identity through pride in his sexuality, political identity, and loyalty to friends. And although diagnosis and special services were mentioned, they never dominated the narratives.

Although The Dark Knight was troubled by his ASD diagnosis, he still defined himself through a desire to help: "I like to care for and protect people … to help and persevere and be an inspiration." For Diana, her ASD diagnosis was a source of pride: "I was happy and excited because it helped me understand who I am." Daredevil attended a special classroom but never mentioned Down syndrome. He touted his work ethic and proudly reiterated multiple times attaining supported living, which allows greater independence than the group homes of most of his peers. Batgirl passingly referenced special education but identified as an athletic person who always maintained a best friend. She liked helping others and wanted to be a teacher, proud of her jobs at school. Sports Guy discussed his mental health diagnosis but never identified as ID and remained determined to earn a general equivalency degree. Even collaborators' secret identities reflected empowerment. Riding a

regular bus to his new school instead of being driven to a special bus was a seminal event for Bus Rider. Sports Guy identified as athletic. Daredevil, The Dark Knight, Batgirl, and Diana (Wonder Woman's alter ego) all identified through a favorite hero (perhaps taking the comic book format literally). And Pudding's alias reflected a playful and optimistic personality. However, it was the desire to give back that most defined collaborators.

Despite stereotypes of social dependence, collaborators consistently expressed a desire to help others. Pudding worked at being a good friend while Batgirl and Diana aspired to serve through teaching and nursing, respectively. Sports Guy—an avid fisherman—always cooked his catches for roommates and remained determined to "be something with my life." Despite working only one day a week, Bus Rider spent part of his earnings on candy to share with roommates. Daredevil was proud of his childhood chores that he maintained in supported living, and always aspired "to help customers" in the food industry. However, motivation extended beyond altruism. Every narrative demonstrated the importance of employment to identity, and all collaborators craved the economic independence and the self-esteem gained through employment.

Daredevil was the most consistently employed, a frequent source of pride. Exploring vocational interests with their grandfathers ranked amongst Bus Rider's and Sports Guy's most cherished memories. Batgirl and Diana were proud of jobs sorting clothes at a thrift shop and bagging groceries. Pudding was out of work but eager to return, and while The Dark Knight had never been employed, he helped with the family hotel business and spoke to his father about taking over one day. However, reality fell far short of their aspirations and collaborators consistently struggled to form realistic and actionable career plans.

Diana and Batgirl had no plan or path at attaining dream jobs in nursing and teaching. In fact, most collaborator training during transition focused on janitorial tasks such as sweeping at a mall or cleaning booths in a restaurant. Bus Rider volunteered and held early paid employment in such settings but did not qualify for PSE training. Pudding recalled little early vocational training, and PSE vocational training failed to result in consistent employment. Sports Guy professed higher ambitions, but admitted his future likely lies in food service, too. Perhaps more focused career training was provided, but nothing that was effective in creating enduring and actionable vocational identities. So, while collaborators did not directly define their identities through community integration, a lack of integrated opportunity clearly affected their self-image.

Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall

This study was built upon the expectation that postsecondary transition would be traumatic and disorienting. However, this turned out to be the case upon entering—not exiting—secondary school. In fact, transition was experienced as overwhelmingly positive. Diana recalled: "When I graduated, I was happy … . I felt ready to be a grown up." Bus Rider and Batgirl also were proud despite missing their friends. For others, leaving school was a relief. The Dark Knight stated he "felt like a free man," while for Daredevil it meant escaping bullying. Both Pudding and Sports Guy dropped out to flee harassment rather than cling to IDEA, although Pudding reflected: "I might have done better or stayed in school if there was less racism and bullying—if people accepted that I like boys." Nevertheless, although transition was not a sudden tumble, all collaborators have struggled to attain independence in adulthood.

None of the collaborators lived independently, and all either depended on or struggled with their families for control. Batgirl admitted: "My mom mostly makes big decisions and controls my life. I'm a little okay with that and a little not." Bus Rider's mom prevented socialization outside his group home, and all four institutional residents relied on staff for leisure, shopping, and other excursions. Batgirl and Diana, both living at home, were the only collaborators to spend significant time with friends, and Diana preferred friends visit her home. None were employed full-time, and all struggled to maintain work when obtained. And even those who earned money seldom controlled it. Bus Rider's parents maintained financial guardianship while Batgirl's mother cashed and controlled her paychecks. Sports Guy depended on money from family. And whatever independence was achieved was easily lost.

Pudding went from apartment living during PSE to supported living and then to a group home because of struggles with appropriate sexual expression. Diana, Daredevil, and Pudding all lost jobs due to COVID-19 and had yet to regain them. And Sports Guy has struggled to achieve residential stability: "I've lived in a lot of group homes ever since I was 17 or 18 and don't like any of them. I would move to one and then they would call 911 and someone would come, and I would move again." Bus Rider met a friend at a fast-food restaurant once before his mother intervened out of fear of inappropriate contact. Therefore, gaining autonomy and community integration was a continuous climb beginning in adolescence with any ground taken easily forfeit by the slightest misstep.

Discussion

While CDT and disability studies continued the march towards greater autonomy and integration, these narratives confirm continued obstacles to community integration upon postsecondary transition for young adults with IDD and noted through studies such as the

NLTS2. No collaborators lived independently or were competitively employed, and all were largely dependent for leisure and social pursuits. Such social barriers are particularly concerning because the "*Happiness is a Friend: Social Support Not Community Integration" Drives QOL* theme demonstrates the importance of personal connections to self-fulfillment. This theme also reflects the importance of family and positive institutional support as expressed in Joly's (2015) *It Takes a Village* theme. Similarly, the "~~Dis~~*Ability Identity: I Am a Complex Person not a Disability"* theme reflects the fractured vocational identities resulting from siloed services, cited throughout transition literature (e.g., Benson et al., 2021; Franklin et al., 2019; Oertle et al., 2021; Plotner et al., 2020). The Dark Knight complained: "The IEP team didn't ask what I wanted to be when I grew up." Collaborator dreams eventually gave way to inconsistent service work promoted by heavily criticized cookie cutter job training centered on food services and janitorial tasks (Hirano et al., 2018; Joseph et al., 2017; Oertle & O'Leary, 2017). This does not prove that underfunded and understaffed professionals are not trying but it does provide insight into how fractured services result in fractured outcomes. Rather than feeling entitled to additional services, collaborators consistently expressed a desire to give back, although their altruism appeared conspicuously absent from transition literature. However, the most striking divergence from prevailing literature was the absence of a perceived policy cliff.

The transition to secondary school caused the primary trauma throughout these narratives, thus "*The Adolescent Earthquake:Transition Begins Earlier Than Expected*" theme. For example, Pudding stated: "I had a good childhood. But I started to have more troubles in middle and high school when other kids started picking on me." The implications for CDS and disability studies in general are profound, suggesting the focus should shift to

much earlier in life. While further study is needed, waiting until 16 to address transition per IDEA may be much too late. Instead, the "*Mountains of Exclusion: The Policy Cliff as a Slow Climb, not a Quick Fall"* theme demonstrates that exclusion and disorientation begin at the onset of adolescence, and collaborators entered adulthood desiring access to greater life skills and social skills training. Sexuality and relationships were among the topics that collaborators most desired knowledge, yet these were conspicuously missing in the literature, even by Rosenbaum and Gorter's (2012) six f-words conceptualizing emerging adolescent participation.

Sports Guy described several girlfriends, although the relationships never lasted long; he expressed disappointment in receiving little guidance on relationships. Bus Rider's long-term relationship ended due to lack of transportation. For Daredevil, Diana and Pudding, sexuality was a source of bullying, with Pudding stating he wished he would have been taught how to touch appropriately. This further reflects the paternalism identified in the theme "*DisAbility Identity: I Am a Complex Person not a* Disability," which also appears in Francis et al.'s (2020) study of the perspectives of PSE students with IDD, which found overprotectiveness was a major impediment to independence and identity. Batgirl, Pudding, and Bus Rider all felt at least somewhat constrained by family while institutional control loomed large for all. This should not diminish the concerns of families and other stakeholders. Guiding children with IDD into adulthood is a complex and demanding process; however, there is clearly room for improvement.

These results also suggest a need to rethink the concept of community integration as defined by engagement of tasks in the community. Collaborators were more interested in giving back than demanding services, and they conceptualized QOL through connections

rather than community engagement. Chang et al. (2013) and Rosenbaum and Gorter (2012) provided broad and inclusive definitions of participation and community integration, which authors such as Black and Lawson (2017), Lee and Morningstar (2019), and Liasidou and Symeou (2018) used to expand the scope of educational outcomes measures, but perhaps we need to go a step further. Integration implies an impetus on individual assimilation per external measures rather than emphasizing individual preferences. For example, Diana rarely left home and would score low on community integration measures but was largely content:

> We stay home, but one time a week my friends … will come over to my house and we play games. I like being at home. For exercise I go on walks with my dad twice a week. We walk around a pond on a street. I also do yoga with my mom.

> By contrast, The Dark Knight helped with the family business and attended the gym

regularly but felt the most alienated. Pudding was still bullied at work and Bus Rider experienced constant turmoil at his group home. They also would score higher on quantitative measures but expressed greater detachment from their community. By contrast, Daredevil, Batgirl, and Diana expressed stronger feelings of self-determination in maintaining social connection and thus expressed higher QOL and community connection. Therefore, as disability studies cultivates more inclusive research, perhaps role participation as determined by respondents should be emphasize over externally imposed ideal of community integration to truly empower this population.

Limitations

While data saturation was achieved, this study was exploratory. Sample size was limited due to complexity of interactions, and sampling through a support agency excluded those who may have achieved full independence. Further, this study was conducted in North

Florida, and both policy and culture can vary significantly by region; therefore, while many universal concerns arose, transferability should not be overstated. Also, while care was taken to capture honest and accurate narratives, memory is imperfect and narrative inquiry concedes that stories are interpretations rather than confirmable facts. The comic book conceit may have also influenced storytelling as demonstrated in the choice of aliases. Finally, this study was limited by my own biases and perspectives, despite reflexive journaling and grounding in CDT. We are all beholden to our experiences, and I chose to value and respect the views of participants, which I find preferable to the alternative bias.

Recommendations

Research

This study highlighted the need to further explore the effects of early adolescence on disability, with specific attention paid to bullying and sexuality specific to IDD, neither of which emerged as deductive codes from existing literature. While efforts have moved transition planning to age 14 in some states, this study supports further investigation into how early transition planning should begin. Further, as one collaborator without siblings failed to make friendships, the effects of siblings on social skills development for persons with IDD may warrant exploration. Finally, community integration as a transition outcomes measure should be examined for cultural bias.

Policy

Although further research is needed, this study indicates IDEA's transition mandate at age 16—and perhaps the age 14 mandate of some states—is insufficient and should begin upon entering secondary school. Also, greater emphasis on bullying prevention for persons

with disabilities should be considered, and persons with IDD may benefit from mandates to address sexuality and relationships as part of life skills training, as these themes failed to turn up in deductive coding yet were consistently cited as a concern by collaborators. Finally, these results connect studies illustrating the problem of siloed services with that illustrating fractured identity formation and indicating a need to promote concrete and enduring vocational identities.

Methodology

This IRB-tested design drew evidence from diverse perspectives such as disability studies and CDT, narrative inquiry, narrative psychology, and occupational therapy. As a methodology, it embraces the ideals and goals of disability studies to promote social justice and equity through amplifying excluded voices. The design may present a blueprint for navigating the collaborative challenges of working with those with IDD while mitigating IRB and other oversite committee reluctance, thereby generating more inclusive research.

Conclusion

While evidence shows young adults with IDD struggle with community integration, this study provided one of the first conceptualizations of postsecondary transition outcomes in the words of those involved. The findings affirm decreased levels of community participation and the need for increased social and life skills training. They further underscore a need for earlier emphasis on transition services while exposing the inadequacy of community integration as an outcomes measure. Collaborators formed empowered identities through abilities and preferences and were hopeful of the future, yet raised concerns about bullying, paternalism, inadequately coordinated services, and a lack of information on sex

and relationships. These narratives described rich inner lives founded upon introspection and complex identify formation, demonstrating that not only does this population desire to speak but deserve to be heard.

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Wheelchair Users' Living Experiences and

Their Perspectives of Accessibility to Public Services in Jordan

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Abstract

This study explores the experiences and perceptions of wheelchair users in Jordan, focusing on ongoing exclusion from public spaces despite the enactment of disability legislation in 1983. It assumes that people with disabilities continue to face significant barriers to full public participation. Using both qualitative interviews and quantitative observations, the study integrates narrative and numerical data through content analysis. Five key themes emerged from the qualitative findings: isolation, frustration, discrimination, negative societal attitudes, and gender-based preference. The study concludes that Jordan's socially biased and structurally inaccessible environment remains a major factor in the persistent exclusion of people with disabilities from the public sphere.

Keywords: environmental accessibility, social stigma, inclusion, Jordan

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The United Nations has acknowledged the right of persons with disabilities (PWDs) to have environmental accessibility leading to their full participation and social inclusion (CRPD 2007). Approximately 1.3 billion people experience some disability, representing 16% of the world's population (WHO, 2022). However, environmental accessibility, education and employment remain the main challenges PWDs face. Systems that were not originally designed with inclusivity in mind face challenges when trying to adapt. In public spaces and infrastructure, accessibility for everyone should be a fundamental guarantee, ensuring equal access to all services.

The Hashemite Kingdom of Jordan has progressively developed its disability policy, beginning with Law No. 12 in 1993 and later Law No. 31 in 2007. Both laws aim to promote equal opportunities for persons with disabilities (PWDs) by mandating accessible environments and supporting full societal participation. Legislative efforts at both local and national levels have sought to expand the presence of PWDs in mainstream education, employment, and public life. These areas are essential for enhancing quality of life, fostering self-reliance, and preserving human dignity. Improved accessibility and community involvement not only promote inclusion but also contribute to the overall well-being of individuals with disabilities (Evans, 2016). Jordan's legal framework also emphasizes the elimination of all forms of discrimination and the creation of a just and equitable society for PWDs.

Building on this legislative backdrop, this article investigates the effectiveness of

Jordan's disability law in promoting environmental accessibility for persons with disabilities

(PWDs), with a focus on the lived experiences of wheelchair users (WCUs). By examining

their access to education, employment, and essential services, the study evaluates how

national policy translates into daily realities. It is grounded in the understanding that access to

the built environment is a basic human right and assumes that full inclusion in the public

sphere is crucial for the socio-economic integration of PWDs. This framework serves as a

meaningful lens for assessing the success or failure of Jordan's disability policy. Barriers to

accessibility may be physical—such as buildings lacking accessible restrooms—or

attitudinal, including assumptions that disabled individuals are less capable (Baart et al.,

2017). Unlike the medical model, which attributes disability to an individual's impairment,

the social model highlights the role of social and environmental barriers. This model is

especially relevant to this study, as it emphasizes the need for supportive social conditions

and critiques the labeling and marginalization that PWDs often endure (Lestari et al., 2020).

Ultimately, the social model reveals how dismantling these barriers can foster equality,

granting disabled individuals greater autonomy, choice, and control.

To deepen this investigation, the article examines the experiences and perspectives of

wheelchair users (WCUs) concerning the effectiveness of Jordan's disability laws—

specifically those enacted in 1983 and 2007—and how these policies shape their daily lives

and participation in mainstream society. It also considers the specific challenges WCUs

encounter within the context of a Muslim-majority society, paying particular attention to the

lived experiences of women. Finally, the study explores how negative societal attitudes and

enduring social stigma contribute to the exclusion of persons with disabilities, underscoring the significance of cultural perceptions alongside structural barriers.

Accessibility towards Social Inclusion

Continuing from this foundation, the social model of disability offers a critical framework for identifying and addressing the barriers that make life more difficult for persons with disabilities. By removing these obstacles—whether physical, social, or attitudinal—societies can promote greater equality and empower PWDs with increased independence, choice, and control. This model also provides a guiding roadmap for both local and international communities to develop inclusive programs that support full participation across all areas of life. According to the World Bank (2007), achieving genuine inclusion requires not only physical accessibility but also the integration of disabled individuals into every facet of society. Accessibility must encompass educational, professional, and social development in order to foster true inclusion. Without meaningful access and active participation, PWDs are denied the opportunity for self-reliance and full human dignity (World Bank, 2022).

Despite evolving policy frameworks, persons with disabilities (PWDs) in Jordan continue to encounter significant barriers in schools, workplaces, and public life. Many of these obstacles arise from entrenched societal attitudes that view disability through a lens of limitation rather than potential (Turmusani, 2003). Teachers, employers, and even family members often lack confidence in the capabilities of PWDs, contributing to patterns of social isolation, illiteracy, and unemployment (Imrie et al., 2007). As Zarb (1995) notes, access to public spaces and facilities is crucial to the well-being of PWDs; when pedestrian systems are inaccessible, the result is not only restricted mobility but also broader forms of social oppression and exclusion. Heiser (1995) similarly argues that the freedom to use public

streets symbolizes civic belonging and the exercise of one's rights. In Jordan, inaccessible infrastructure continues to undermine that freedom. To assess the degree of social inclusion, the World Bank (2011) identifies three key domains: education, employment, and access to essential services—domains that will serve as analytical benchmarks in this study. Notably, few existing studies have employed qualitative methods to capture the voices of wheelchair users (WCUs) and to examine their firsthand experiences navigating public spaces and services.

Expanding on the need for qualitative insight, Smith (2016) emphasized that the experiences and perceptions of wheelchair users (WCUs) in low- and middle-income countries remain underrepresented in research and must be more fully integrated into policy discussions. Supporting this broader view, Emily Brooks and Mariette Bates (n.d.) argue that disability is not a fixed condition but a social construct, shaped by cultural norms, historical context, and evolving human understanding. From this perspective, the meaning of disability varies across time and place. Armstrong (2010) extends this idea by contending that conditions such as developmental, learning, and mental health disabilities are socially defined and context-dependent. As he writes, "No brain exists in a social vacuum. Each brain functions in a specific cultural setting and at a particular historical period that defines its level of competence" (p. 15). He further observes that "being at the right place at the right time seems critical in defining whether you will be regarded as gifted or disabled" (p. 15). These insights challenge static definitions of disability and underscore the importance of cultural awareness in shaping both inclusion and exclusion.

Methodology

To ground these theoretical insights in lived experience, this study draws on data from in-depth interviews with a sample of seven wheelchair users (WCUs). Researchers employed non-directive, open-ended questions designed to elicit detailed accounts of participants' daily lives and the environmental and social barriers they navigate. The methodology section outlines the sampling process, interview design, and analytic approach in detail. All interviews were conducted in Amman, Jordan's capital, providing a focused urban context for interpreting the findings. The Data is categorized under three major topics: education, employment, and essential services.

Sample selection procedures

Participants were identified with the assistance of local Chiefs, as no centralized registry or institutional database existed to provide names or contact information for wheelchair users. The final sample consisted of seven respondents—six males and one female (see Table 1).

Table 1

Characteristics of the WCUs' Sample in Jordan

	Age	Employment Status	Marital Status	Gender	Formal Edu.	Cause of Disability
Respondent1	36	Employed	M	M	H. School	Polio
Respondent 2	21	Employed	S	M	Graduate	Polio
Respondent 3	16	Student	S	M	H. School	Polio

Respondent 4	20	Unemployed	S	F	None	Polio
Respondent 5	35	Employed	M	M	H. School	Accident
Respondent 6	19	Student	S	M	University	Polio
Respondent 7	40	Unemployed	M	M	None	Polio

Limitations of sample selection

Gaining access to the targeted sample posed a significant challenge, as wheelchair users (WCUs) in Jordan were not registered in any centralized database. Nevertheless, through the assistance of tribal Chiefs across various neighborhoods in Amman, the researchers were able to identify and recruit a sample of 12 adult WCUs residing in the capital. The initial inclusion criteria required that participants be permanent wheelchair users and residents of Amman City.

Despite identifying twelve eligible participants, five WCUs (three females and two males) ultimately declined to take part in the interviews for reasons that remain unknown. As a result, the final group of seven participants was assembled with the continued help of local Chiefs. Cultural norms also shaped the interview process. For instance, the sole female participant was interviewed in the presence of her family members, in accordance with Jordanian custom and Islamic tradition, which generally prohibits a woman from meeting alone with an unfamiliar man in a private setting. This cultural constraint may have contributed to the withdrawal of the three female participants. Notably, during the interview, the family members present did not interfere with the discussion. Additional limitations emerged from the Chiefs' role in the process; many would only refer WCUs already known

to them, meaning the researchers had no influence over who ultimately agreed to participate. Thus, the final sample reflected not only willingness but also the reach of local networks. The gender imbalance in the sample also reflects broader societal dynamics, as familial restrictions often limit female participation in public research. Nevertheless, this limitation aligns with regional trends, where disability prevalence rates are generally higher among men than women in Arab countries (ESCWA, 2018).

Data Collection and Procedures

To further explore these complex dynamics, in-depth interviews were conducted to capture WCUs' perspectives on their daily lives and the accessibility challenges they face in the public sphere. This qualitative approach prioritized the voices of those most directly impacted—positioning WCUs as the true experts on the subject. The interviews focused on participants' backgrounds, personal experiences, and interpretations of how disability legislation has influenced the built environment. Particular attention was given to how these laws shape, support, or fail their day-to-day navigation of public spaces and opportunities for inclusion.

To ensure participant comfort and accessibility, in-depth interviews were conducted in mutually agreed-upon locations, including the homes of local Chiefs and the WCUs themselves. Each interview lasted approximately 90 to 120 minutes. All seven participants were fully informed about the nature of the study and the intended use of the data. However, given the lack of prior relationships between the researchers and respondents, it was necessary to adopt a more relaxed and informal interview style to facilitate open and honest communication.

Following standard qualitative procedures, all face-to-face interviews were audio-recorded. Transcription began immediately after each session while participants' views and comments remained fresh in memory. Full transcription was deemed unnecessary, as some portions of the recordings were not directly relevant to the research focus. Selective transcription prioritized segments most aligned with the study's core themes—particularly those revealing how participants linked the causes of disability to religious interpretations, a connection that emerged as a recurring thread throughout the interviews.

Methods of Data Analysis

To analyze the interview data, a content analysis approach was employed to identify recurring themes and patterns in participants' responses. This method is commonly used in qualitative research to distill meaning and highlight core consistencies (Patton, 2002). The decision to use content analysis aligned with the study's aims and the nature of the data collected. Given the qualitative format, manual coding served as the primary method of analysis. While computer-assisted tools such as ATLAS, Nudist, or NVIVO are often used in qualitative research, they were not practical in this case. Using such software would have required translating all recorded and handwritten data from Arabic—the respondents' primary language—into English before uploading it into a digital database, adding an extra layer of time-consuming processing. Manual coding, therefore, offered a more efficient and context-sensitive alternative.

The next phase of analysis involved data reduction using a conceptual framework informed by Catanzaro (1988) and Downe-Wamboldt (1992), which emphasized identifying 'accessibility problems' as expressed by participants. Transcripts were reviewed multiple times to grasp the overall meaning before extracting units—specific words or phrases—

directly relevant to the study's objectives. Each meaningful unit was assigned a code, with codes emerging inductively from the data rather than being predetermined. This approach allowed the analysis to remain grounded in participants' lived experiences and language, ensuring that themes reflected their perspectives authentically.

The process of reviewing and categorizing the data was guided by Catanzaro's (1988) criteria for content analysis, ensuring that emerging categories were both meaningful and grounded in the data. The next step involved comparing samples of the original interview transcripts against the identified categories. This comparison allowed the researchers to classify information into coherent patterns, overarching themes, sub-themes, sub-sub-themes, and key insights. These major themes, along with additional analytical notes, served to clarify and support the presentation of findings in the next section.

Building on the categorization process, content-based analysis was employed to identify participant responses to key questions and to assess the frequency of shared concerns. When discussing their experiences within the surrounding environment, participants repeatedly emphasized several core themes. Across most interviews, recurring issues included frustration, isolation, negative societal attitudes and stigma, limited accessibility of buildings, and exclusion from socio-economic participation.

Ethical Constraints

In line with ethical research standards, participants were fully informed that their involvement was entirely voluntary. Ethical clearance was obtained prior to data collection, and all respondents received detailed information about the study's purpose, the nature of the questions, how the data would be used, and the measures taken to ensure confidentiality. They were also informed of their right to withdraw at any time, including during the

interview, and their right to decline any question they found uncomfortable. Additionally, they were provided with contact information should they have second thoughts about participation. A formal consent form—outlining the project scope, interview format, potential risks, and confidentiality protocols—was reviewed and approved by all participants, who gave their informed agreement to proceed.

Findings

Turning to the findings, this research explores the everyday challenges and obstacles faced by wheelchair users (WCUs), as expressed through their own experiences and perceptions. Participants were asked to describe the specific difficulties they encounter in navigating daily life. Based on their responses, several key themes emerged that illustrate the range and nature of the barriers they face:

Frustration

In response to the question, *"Do you feel frustrated by being a wheelchair user?"* all participants initially expressed that they did not feel frustrated by their disability itself. Instead, their frustration stemmed from external conditions—particularly poor urban planning and design. They placed significant blame on the Planning and Design Department for failing to create an accessible built environment and criticized the Municipality for its inaction regarding blocked sidewalks and pedestrian paths. As one respondent (M2) explained, *"I feel frustrated in the worst possible way when I should ask people for help."* Echoing this sentiment, respondent M6 stated: *"Whenever I decide to go out and about, I feel nervous as I have to beg many people to help me overcome many architectural barriers on the pathways, sidewalks or entering public buildings."* After a pause, he added: *"It is a risky journey to*

negotiate the public realm in Amman city without being accompanied by someone. It is a real nightmare." (Respondent M6).

Negative attitudes and isolation

In contrast to the male respondents' focus on architectural barriers, the female participant emphasized a deep sense of social isolation. She acknowledged, *"I feel neglected, and this negligence has become my lifestyle—though it was not my choice but imposed on me."* She continued, *"I am not happy with the status of isolation, not just because I cannot go out—as most non-disabled women in Islamic society are confined within their homes; instead, I feel my fellow human beings' negative attitudes destine my future, not God as claimed."* She held the Jordanian government responsible for failing to address these issues, stating that it has neither challenged public attitudes nor taken meaningful steps to combat gender discrimination. *"The government does not use mass media to introduce the potential of people with disabilities to the general public,"* she explained. *"As a female, I cannot speak to the authorities because no one will listen to a disabled female."*

This pointed critique of the government emerged despite the existence of legal protections affirming gender equality under Jordan's disability law. As stated in the legislation, "the right of equality between men and women is secured" (Section D, Article 3, 31/2007). However, the female respondent (F1) offered a more sobering counterpoint:

As a female, I cannot enjoy equal rights with a male in a traditional Islamic society, which means I was disabled by religion and culture before my physical disability. It means I suffer double discrimination for being a female and having a physical disability.

Her response underscores the disconnect between legislative intent and lived reality, revealing how intersectional barriers—cultural, religious, and structural—compound exclusion and shape identity in ways the law alone can not address.

Building on these gendered insights, F1's quotation aligns with findings by Thompson (2018), who reported that disabled women in Jordan face greater vulnerability to abuse and stigma than their male counterparts. It is, therefore, not surprising that women in Arab Muslim societies often experience what is referred to as double discrimination. Throughout the interviews, respondents frequently used strong terms such as *"ignored," "neglected,"* and *"lack of potential"* to describe their feelings of isolation and their perception that decision-makers deliberately overlooked their needs. These statements suggest that mutual understanding plays a vital role in fostering inclusion. Without it, persons with disabilities remain marginalized and socially excluded. This exclusion appears to be driven by persistent negative attitudes, limited public awareness, and widespread misconceptions about disability. To further probe the issue of inclusion, participants were also asked whether they had ever been involved—or would like to be involved—in the planning and design of the built environment.

Continuing the discussion on inclusion, analysis of the interviews revealed that participants expressed a mix of both despair and aspiration when reflecting on their involvement in design and planning processes. As respondent M6 explained:

> I have never been involved in or even asked to participate in any design or planning project locally, let alone national planning, because negative attitudes of service providers would not allow them to consider PWDs as people who got an idea or knowledge to add.

He further reflected, *"It would be a great opportunity to participate and contribute my idea to the design of my living environment."*

Extending this theme of exclusion, the female respondent (F1) expressed even stronger feelings of resentment regarding her lack of involvement in community decision-making:

I have never been asked to attend a local community meeting, and I do not expect those highly educated designers or planners waiting to hear from me as a low-educated person to advise them how to design.

She continued, *"Service providers, designers and planners, however, are part of this discriminating society which has always had negative attitudes towards [PWDs] in general and females in particular."*

Social stigma

Building on these personal accounts, the concept of social stigma must be understood as culturally and structurally dependent, shaped by societal norms, values, and power dynamics. Consequently, perceptions of stigma vary from one community to another. The World Health Organization (2020) defines social stigma as *"an adverse connection between an individual or group of individuals who share certain characteristics and a particular situation."* In the context of Jordan, Jalal and Gabel (2014) argue that society often labels persons with disabilities (PWDs) as abnormal, dependent, and inherently stigmatized. Such classifications not only harm PWDs but can also extend to their families, friends, and allies—reinforcing cycles of exclusion and limiting full societal participation.

Despite encountering people's negative attitudes and social stigma, Muslim PWDs referred their disability and everything happening in their lives to the will of Allah (God). This belief relieves them and makes them feel resilient and calm when facing problems or

difficulties. M5 respondent, for instance, pointed out that, *"People staring at me make me feel out of place and give me a strong sense of discomfort and insecurity."* He added, *"But what can I do? It is not my choice; Allah (God) decided so to test my loyalty."* (Respondent M5)

This belief implies a lack of awareness and understanding on the part of communities that often endorse this false idea about WCUs. The media needs to play a stronger role in combating these prejudices.

Basic services

In addition to social attitudes, the issue of access to essential services emerged as a central theme, reflecting the critical connection between disability rights and the fulfillment of basic needs such as education and employment. Accessibility was consistently framed by participants in relation to these domains, as well as broader access to the public sphere, all of which are foundational for achieving inclusion and equal opportunity.

Access to education

Building on the importance of accessibility, education emerged as a critical theme due to the significant challenges persons with disabilities face in achieving independence and opportunity. As Blunkett (2008) notes, a strong education is essential for helping individuals with disabilities overcome daily barriers and live more autonomous lives. However, ESCWA (2018) emphasizes that in Arab countries, PWDs are significantly less likely to attain any form of education compared to persons without disabilities. Similarly, the Convention on the Rights of Persons with Disabilities (CRPD, 2017) reports that in Jordan, the proportion of persons without disabilities attaining International Standard Classification of Education (ISCED) level one or higher is 1.6 times greater than among PWDs. Additionally, the United

Nations Department of Economic and Social Affairs (UNDESA, 2018) highlights a striking gender disparity, noting that women with disabilities are three times more likely to be illiterate than men without disabilities.

Further reinforcing these challenges, respondents highlighted the damaging impact of social perceptions on their educational development. Many noted that educational authorities and local community members often show little confidence in the capabilities of wheelchair users, viewing them as burdens. This attitude, they argued, poses an even greater obstacle than physical barriers. In contrast to more developed contexts, the school attendance rate of PWDs in many developing countries remains negligible—largely due to the lack of inclusive infrastructure and accessible educational environments. As respondent M4 expressed with frustration, *"Changing the discriminatory attitudes of our society towards PWDs is far more difficult than installing an access ramp"* (M4 respondent).

Despite their notable educational achievements, participants still identified accessibility to educational institutions as a persistent barrier. For example, a 21-year-old respondent (M2), a university student in Amman, explained:

Accessible building of the faculty I am attending was the main factor that influenced my choice of my university course rather than my interest in the specific academic course. Simply because it was more accessible than the other buildings of the same university.

Further highlighting systemic gaps, the Disability Monitor Initiative (DMI, 2009) reported that the right of disabled students to access higher education is still not being adequately fulfilled. This failure is largely attributed to poor coordination between disability support institutions and the ineffective enforcement of higher education policies. Although Jordan is a signatory to several international declarations and has even received international

recognition for its work on disability and accessibility, the reality on the ground tells a different story. The government's *Education for All* program, for instance, has not met its goals and, for many PWDs, remains a distant ideal rather than an achievable reality. As a result, most respondents expressed disappointment and skepticism regarding their access to vocational education—an avenue they saw as critical for future employment opportunities. The majority (71%) of respondents' statements showed complete dissatisfaction and resentment about the unemployment problem, something which "leads to their dependency" (Turmusani, 2003, p. 66).

Expanding the scope of responsibility, respondents also criticized families—particularly those from low-income backgrounds—for their lack of investment in the education of disabled children. Many families, they noted, are unable to afford private schooling and instead choose to keep their children at home. In some cases, this decision is driven by financial constraints; in others, it stems from shame or social stigma. Rather than supporting their children's education, some families involve them in household labor. A few respondents also mentioned more troubling cases in which children with disabilities were reportedly exploited or made to beg in public to generate extra income for the family. While these accounts were not formally documented, they were noted as part of the co-author's direct observations.

Adding a powerful gendered perspective, the female respondent (F1) shared a personal account of unequal treatment within her own family compared to her non-disabled siblings:

I am now 20 years old, and my father did not allow (let alone encourage) me to go to school while my sisters and brothers are going to school. I wish I were given a chance.

She added:

> Traditionally females are not encouraged or obliged to seek education to avoid
> harassment which may put the family's pride at risk. The traditional public believes
> that females have no financial obligation to fulfil as the family caters for them before
> marriage or the husband after marriage. This belief has exacerbated the situation even
> further for me as a disabled female. (F1 respondent)

Extending beyond the Jordanian context, familial discrimination against persons with disabilities is a broader trend observed across Arab societies. In Lebanon, for instance, families with more than one disabled child often treat sons and daughters unequally. Lakkis (1997) reports that in one such case, a family with both a son and a daughter with motor disabilities provided a wheelchair for the son but did not consider purchasing one for his sister. This example illustrates how gender bias compounds disability discrimination within the private sphere.

Access to employment

Turning to the issue of employment, it stands as a cornerstone of economic participation and a key determinant of a decent standard of living. For persons with disabilities (PWDs), involvement in the labor market fosters not only economic independence but also social inclusion, individuality, and dignity. In support of this, Article 27 of the Convention on the Rights of Persons with Disabilities (CRPD) affirms the full right of PWDs to work on an equal basis with others. While employment remains a persistent challenge for PWDs in many developing countries, shifting paradigms in the developed world offer hope. These global advancements raise expectations for improved employment opportunities and better quality of life for PWDs in other growing economies.

Building on these structural barriers, the traditional attitudes of families and communities toward the employment of PWDs remain overwhelmingly pessimistic. Expectations for disabled individuals to achieve financial independence or contribute economically are often minimal. As Oliver (1990), a disabled professor, poignantly argues: It is not personal restrictions, of whatever kind, which caused the problem, rather negative society's attitude that acts as a barrier to accept PWDs or provide them with appropriate services to meet their needs (Oliver, 1990, p.32). This underscores the idea that social exclusion is constructed not by impairment itself, but by entrenched societal beliefs and absence of structural support.

Further exposing the disconnect between policy and practice, Jordan's disability law obliges both public and private sectors to provide PWDs a fair chance at employment. However, even within the public sector, hiring procedures often remain discriminatory (World Bank, 2007). Conditions in the private sector are reportedly worse, with PWDs frequently relegated to low-level positions (World Bank, 2004). Such workplace discrimination stands in direct violation of Article 3, Section C of Law No. 31/2007, which guarantees PWDs the "equal right to employment opportunities" (Jordan disability law, 31/2007).

In response to the question, *"Which barrier(s) affected your employment opportunity?"* respondents unanimously pointed to the failure of authorities to provide an accessible environment—particularly with regard to public transportation. Inaccessible transit systems were consistently identified as the primary obstacle preventing employment. As respondent M4 explained, *"The pedestrian sidewalks either have an uneven surface with a high curb or,*

if it has a levelled surface, then [they're] blocked by private vehicles parked" (M4

respondent).

To corroborate participants' claims, the researchers conducted site visits to observe the

built environment and document the reported architectural barriers. During these visits,

photographs were taken as visual evidence. One recurring issue was confirmed: sidewalks

were largely inaccessible due to uneven, high curbs (see Figure 1).

Image 1: Uneven sidewalk act as a barrier for WCUs.

Figure 1

Uneven sidewalk acts as a barrier for WCUs.

WCUs may also be blocked by cars illegally parked on the sidewalks (Figure 2).

Image 2: Sidewalk used as a car parking zone in Amman.

Figure 2

Sidewalk used as a car parking zone in Amman.

Wheelchair or pram access is also blocked by trees and cement planter boxes (Figure 2 & 3).

Image 3: Trees blocking the sidewalk in Amman

Figure 3

Trees blocking the sidewalk in Amman.

Compounding the issue, this short-sighted urban planning was carried out by authorities tasked with ensuring the safety and accessibility of public spaces for PWDs. Instead, they permitted construction debris to obstruct sidewalks, forcing pedestrians—especially wheelchair users—to walk along roadways, where they are exposed to the very real danger of being struck by passing vehicles. (see Figure 4).

Image 4: Construction's debris blocking the sidewalk

Figure 4

Construction debris blocking the sidewalk.

Despite legal frameworks promoting inclusion, PWDs in Jordan continue to face numerous architectural and social barriers that discourage them from pursuing education, employment, or independent living. Most respondents (57%) reported that their family members believe it is unsafe for them to go out on their own. This concern is not unfounded, as motorists in Jordan routinely ignore pedestrian safety—failing to slow down or stop even when individuals, including WCUs, are visibly attempting to cross the road. On multiple

occasions, the co-author—himself a wheelchair user—waited approximately 30 to 45 minutes to cross a single street, until someone helped him cross.

Adding to the gendered challenges, the female respondent (F1) shared a powerful reflection on her restricted mobility:

> I rarely leave my home as there is no job for disabled females and spend my days either sitting on the balcony or watching TV. I feel like a prisoner as the only time I go out is when there is a family occasion to attend. (F1 respondent)

In traditional Islamic culture, women are expected to be accompanied by an immediate male family member when leaving the home—an expectation that becomes even more demanding when the woman is a wheelchair user. Although such gender-based restrictions contradict Jordan's civil rights laws, discrimination against women—particularly those with disabilities—continues to be reinforced through cultural norms and daily practices.

Further intensifying these concerns, families are often more protective of daughters with disabilities and are generally reluctant to allow them to work, fearing for their safety. Many believe that disabled women *"can easily be exploited and harassed."* This fear gained public legitimacy following a BBC Arabic exposé that aired secret footage revealing the abuse of children with disabilities by their teachers and caregivers. The report was the result of a 2011 undercover investigation by Henan, an amateur journalist, who documented instances of physical abuse and neglect in private care centers for children with mental disabilities in Jordan. Henan's investigation was supported and supervised by the Arab Reporters for Investigative Journalism (ARIJ) network. Broadcast on 15 May 2012, the report sparked public outrage and became a national scandal, raising serious questions about accountability and the treatment of vulnerable individuals in Jordanian institutions (BBC Arabic, 2012).

Discussion

Jordan holds the distinction of being the first country in the Arab world to enact a disability law modeled after the Americans with Disabilities Act (ADA) passed in the United States in 1990. This legislation acknowledges the legal rights of persons with disabilities (PWDs) and aims to enhance their social inclusion. The present study evaluates the practical success or failure of this policy through the lived experiences of a sample of seven wheelchair users (WCUs) in Jordan. While the law theoretically guarantees equal rights—particularly regarding access to public spaces, education, and employment—the respondents' accounts revealed widespread dissatisfaction. Their testimonies reflected clear frustration over persistent inaccessibility and exclusion from key services that the law is intended to provide.

Continuing the examination of policy versus practice, the law promised that PWDs would receive the social resources necessary for effective daily functioning. Nevertheless, findings from this study revealed that educators, employers, and service providers have not developed a consistent tendency toward the inclusion of PWDs in mainstream society. Despite differences in background and medical condition, most participants expressed similar feelings of dissatisfaction and unhappiness—particularly regarding their access to public services, which fell far short of what the law had guaranteed. This lack of accessibility and poor service delivery was further confirmed by the researchers' field observations. According to the interviewees, these issues are not confined to the capital city of Amman but are also prevalent in other towns across Jordan.

Reinforcing these challenges, respondents consistently identified negative societal attitudes as the primary factor fueling bias, isolation, and exclusion of wheelchair users

(WCUs) from public life. The problems faced by WCUs in Jordan mirror those reported globally. For instance, the European Commission notes that many PWDs in Europe continue to lack equal access to schools, workplaces, services, and information. This suggests that raising public awareness around disability remains a critical, and often neglected, need. Without sustained efforts to shift societal attitudes, exclusion will persist—regardless of physical accessibility improvements. Even where architectural access has advanced, social stigma and misinformation continue to limit the full participation of PWDs. This concern was also raised by respondents, who stressed the importance of awareness campaigns. Their view aligns with Article 19 of the CRPD Committee and its various Concluding Observations (COs), which call upon the Jordanian government to ensure the effective dissemination of information to PWDs and their families. As Harper et al. (2022) note, this information should empower individuals to understand their rights, access available services, and pursue independent lives based on self-determination and full social participation.

In parallel with education and employment, access to other essential services reflects a similar pattern of disconnect between policy and implementation. For instance, although the Jordanian Ministry of Education officially endorses an inclusive education policy, a Human Rights Watch (HRW) review of the national budget revealed that no specific funding was allocated to support inclusive education practices. International standards emphasize the right to inclusive education, promoting the integration of children with and without disabilities in mainstream schools. Nevertheless, Jordan's Ministry of Education allocated only 0.4% of its budget to "special education," effectively maintaining a segregated approach to educating children with disabilities. Similarly, the Vocational Training Corporation dedicated just 1%

of its 2019 budget to increasing the participation of women and people with disabilities in training programs (HRW, 2019).

Despite the theoretical guarantees of equality under the Jordanian Constitution and the more recent Act of Rights of Persons with Disabilities, the reality on the ground tells a different story. Employment rates for PWDs remain strikingly low, with only 1% employed in the public sector and 0.5% in the private sector. Of these, 23.8% are men, while a mere 4.8% are women. By contrast, employment rates for men and women without disabilities are 61.4% and 13.5%, respectively. These disparities illustrate the compounded discrimination faced by women with disabilities, whose participation in the labor force is especially limited. As echoed by respondents in this study, this pattern is not unique to Jordan but is reflective of a broader trend across the Arab region. When multiple individuals with disabilities exist within a single household, male members are more likely to receive educational opportunities and access to assistive technologies.

According to participants, the limited success of Jordan's disability law can be attributed primarily to two key factors:

1. A lack of sufficient funding allocated to disability-related programs, particularly in employment and education (HRW, 2019); and

2. A lack of inclusive understanding and practice among implementing institutions.

In contrast to developing countries like Jordan, barriers such as social stigma and gender-based discrimination against wheelchair users are far less prevalent in many developed Western societies. Michael Page, director at Human Rights Watch, stated that Jordan's disability law is excellent on paper. However, it means nothing for people with disabilities if the government does not implement it. Nevertheless, some progress has been made—

Jordan's law has played a role in legally protecting the rights of persons with disabilities, even if practical implementation remains uneven.

Conclusion

Extending this analysis, environmental barriers and a lack of societal acceptance—both common across Arab Muslim countries—have negatively impacted the satisfaction levels of most respondents. Notably, 50% of the sample expressed dissatisfaction with the authorities for failing to consult them during the design of physical environments and service provision. This frustration appears to stem from deeply rooted negative social attitudes, which play a central role in shaping a disabling environment. Consistent with the social model of disability, 72% of respondents identified these social attitudes as the primary factor contributing to their isolation. Based on participants' statements, it can be concluded that although the social model of disability has gained recognition in Jordan in recent years, the physical challenges faced by individuals with disabilities remain under-examined. A more accurate and comprehensive understanding of disability must account for both social and environmental dimensions.

Despite Jordan's disability law guaranteeing the right to education and employment for persons with disabilities (PWDs), the findings of this study reveal that access to these fundamental rights remains significantly lower for PWDs compared to people without disabilities. The data also highlight pronounced gender disparities, with women with disabilities experiencing even greater exclusion. As in other Arab Muslim societies, Jordan's patriarchal structure contributes to the double discrimination faced by disabled women, who are often excluded from domestic policy and overlooked in both local and national agendas. Respondents consistently identified themes such as frustration, isolation, social stigma,

discrimination, and negative societal attitudes as the main barriers undermining their daily lives. This alignment in participant perspectives allowed the researchers to conclude— with a reasonable degree of confidence— that these factors play a central role in the ongoing exclusion of wheelchair users. The study's findings further underscore that Jordan's disability law, while progressive in its language, has yet to achieve its intended outcomes and must be implemented more effectively.

Nevertheless, the success of any policy depends not only on the development of a well-crafted legal framework, but also on the establishment of effective implementation mechanisms and consistent performance monitoring. A law's impact is measured by its outcomes, not its intentions. Based on the findings of this study, there remains a significant gap between the promises articulated in Jordan's disability law and its real-world achievements. Bridging this gap is essential if the needs of persons with disabilities (PWDs) are to be adequately addressed and social inclusion truly realized. A critical first step in closing this divide is fostering a shift in public attitudes. Changing societal mindsets must become a central priority. While it is important to avoid overgeneralizing the situation in all developing countries—each national context is distinct—the experience of disability policy in Jordan offers a valuable case of formal legal recognition for PWDs, including wheelchair users (WCUs), even if the implementation continues to fall short.

Recommendations for policymakers

To move disability policy forward, cultural factors and political will must work in tandem, particularly in developing and implementing policies that improve the lives of PWDs—especially WCUs, who are the focus of this study. Most importantly, policymakers and planners must recognize that the true measure of any policy's success lies in how

effectively it facilitates PWDs' access to the public sphere and their integration into socio-economic life and mainstream society. To uphold the rights promised under the disability law, the Jordanian government should reevaluate its annual budget allocations to ensure that sufficient funds are directed toward implementing inclusive policies and programs. Special priority must be given to making public buildings and services fully accessible to individuals with diverse types of disabilities. Moreover, PWDs themselves possess valuable lived expertise and should be consulted, empowered, and actively involved in policy formulation and implementation processes.

Recommendations for persons with disabilities

Finally, it is important to reject the notion that a "bridge" is needed between disabled and non-disabled individuals, as they are not two separate communities but integral parts of the same social fabric. True inclusion requires policies that accommodate *all* members of society without distinction. However, this study found that many persons with disabilities declined to attend public events when confronted with physical barriers, underscoring how exclusion persists in daily life. Negative societal attitudes are more likely to fade when PWDs are visible and actively participating in social spaces. In other words, accessibility fosters connection—bringing people into contact with one another and shifting perceptions from "different" to simply "normal." PWDs are entitled to full autonomy and must be consulted on matters that directly affect their lives, including health, education, employment, rehabilitation, and community living. To realize accessibility beyond mere mobility, guaranteed access to education, employment, and social services must be made a core priority.

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Research Articles and Essays

They Deserve More:

Social Justice and the Disability Support Workforce Crisis

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Abstract

Internationally, a shortage of support workers caused by low pay is threatening the quality of life for adults with intellectual disabilities. In Illinois in the United States, advocates formed the *They Deserve More* coalition to raise wages. This paper uses insights from moral and political philosophy to analyze its motto—who is the *they*, what does it mean to *deserve*, and what is the *more*.

Keywords: direct support professionals, disability rights, moral desert, social justice

They Deserve More:

Social Justice and the Disability Support Workforce Crisis

"I'm not going to learn your name for a year," the disability agency manager announced. "I heard that said by an adult with intellectual and developmental disabilities (IDD) to a new staff member at his group home." I interrupted: "I know why. It's about turnover. The resident knew the worker would probably leave the job soon." The manager smiled sadly and nodded.

Developed nations are in the process of deinstitutionalization—moving disabled people out of segregated settings with standardized services into integrated community locations with individualized support. In the United States, 225,000 adults with IDD live in small group homes and attend day activity centers (Residential Information Systems Project, 2021). My son David is one. Many like him have a range of limitations and require lifelong supervision with everything from eating, bathing, and taking medication to job and life skills training. That assistance comes from Direct Service Professionals (DSPs).[1] But a severe shortage of DSPs is threatening services for people with IDD. Litigation and advocacy have nudged states toward boosting wages and improving staff levels. In Illinois in the United States where David lives, advocates formed the *They Deserve More* coalition to lobby state lawmakers to raise DSP pay.

Eva Feder Kittay (1999) highlights the burdens of unpaid caregivers—family members, usually women—who look after dependents at home.[2] In this paper, I discuss paid caregivers—DSPs who support people with IDD. I focus on agency-employed staff, but there is also a shortage of workers for self-directed care. I emphasize wages, although lack of career opportunities also contributes to the workforce crisis. I spotlight Illinois as a case study

of a prevalent and persistent national and international problem.

Disability studies examines disability within social, cultural and political contexts. It promotes awareness of the experience of disabled people and advocates for social change (since disability is more a socio-political than a medical phenomenon). In this paper, I reflect philosophically on a grassroots effort to influence public policy. Sometimes—Christopher Bennett (2017, p. xviii) says—philosophers are "humbled by the wisdom of highly skilled practitioners .... [and] all philosophy can do is to seek to give a theoretical articulation to such wisdom." The professionals and advocates who chose the name *They Deserve More* knew what they were doing. My aim is to interpret the label: they (people with IDD and DSPs) deserve (as an entitlement, not a favor) more (generous funding from a wealthy nation). I first summarize empirical evidence concerning staff shortages internationally, across the United States and in Illinois. I then use moral reasoning to shed light on the meaning of each aspect of the *They Deserve More* slogan.

Empirical Evidence

Around the world and across the United States, service agencies face staff shortages and its result—decreasing program quality for people with IDD.

Personal Testimony

Personal narratives enable understanding of social contexts. Before presenting quantitative data, I give qualitative description of the lived experience of one adult with IDD. While anecdotal, my son's story is typical.[3]

David's group home of four high-need men is often understaffed—it requires two DSPs, but often only has one. Basic care can be inadequate. David cannot brush teeth without supervision, but a single worker finds it difficult to assist him with three other residents to

monitor. He is—at age 32—showing signs of gum disease. David is nonverbal, so it takes months for a DSP to learn how to work with him and understand his communication patterns. But there is a constant turnover of regular and substitute staff who do not know his unique needs, strangers with whom he is not comfortable. Having only one DSP limits community outings: all four men have to want to go to McDonald's or a holiday parade—if even one does not, then the group cannot go since none can be left alone. Weekends are particularly difficult with rotating and unfamiliar house staff.

David's typical day is spent in a segregated activity center. It lacks sufficient staff to take him into the community or conduct meaningful activities. What he should be doing is integrated recreation (as when his mother or I take him to Special Olympics sports programs) and volunteering (as when he and I stock shelves at a food pantry). At his congregate center, he is in a group of 10 individuals supervised by one DSP. Community recreation or volunteering would mean small groups with a staff-client ratio of 1:3. Worker shortages make that impossible.

The barely adequate services David receives are not the fault of his agency, which meets the highest accreditation standards. It is the fault of a poorly funded public disability system that harms both service-users and DSPs.

Sociological Facts

A skilled and reliable DSP workforce is the linchpin of disability services, but staff shortfalls affect all developed countries.

The International Staffing Shortage

Social services in Europe face a labor shortage with high turnover and vacancy rates (European Association of Service Providers for Persons with Disabilities, 2019; European

Public Service Union & Federation of European Social Employers, 2020; Federation of European Social Employers, 2024; Lethbridge, 2017). Agencies have difficulty recruiting and retaining qualified staff. Pay is poor (hourly wages are 21 percent lower than the average for all workers) and career development opportunities are insufficient. Working conditions—variable hours in jobs that are emotionally and physically demanding—are undesirable. In Finland, the shortage of care workers means that some agencies cannot provide necessary support (S. Miettinen, personal communication, September 2023). In England, where government has tightened budgets, agencies struggle to find and keep staff (Courtenay, 2018; Equality and Human Rights Commission, 2017; Public Health England, 2019). In Ireland, low pay, unpredictable schedules and increased responsibility create a shortfall of care staff (Fleming & Taylor, 2006). In The Netherlands, 180,000 of the 1.2 million care workers change jobs every year—and almost half leave social care (European Public Service Union & Federation of European Social Employers, 2020, p. 5).

Australia has thousands of unfilled care positions. Turnover is high; the disability workforce lost 200,000 employees between 2021 and 2024 because of poor pay and limited career pathways. Staffing challenges are particularly acute in remote communities and for individuals with complex needs (Commonwealth of Australia, 2021, pp. 10-20). New Zealand also has a shortage of caregivers. Workers leave because the job is stressful, hourly pay is near minimum wage, and there are few chances to advance in the field. Agencies hire less experienced workers, resulting in compromised care (Jorgensen et al., 2009).

The underlying cause in all jurisdictions is lack of resources. Employees have trouble finding jobs with fair pay, stable working conditions and career development. Service-users experience denial of services, closure of programs, decreased quality of support and long wait

lists (Federation of European Social Employers, 2024, pp. 2-3). According to the European Association of Service Providers for **Persons with Disabilities** (2019, p. 4), the "detrimental impact [that lack of staff has] on ... person-centered and community-based forms of care and support ... cannot be underestimated." Improving recruitment and retention must become a budget priority for policymakers.

The U.S. Staffing Shortage

In the United States, 1.28 million DSPs work in various settings. Numerous reports (American Network of Community Options and Resources, 2022 and 2023; Institute on Community Integration, 2018; National Alliance for Direct Support Professionals, 2024; National Core Indicators, 2022; President's Committee for People with Intellectual Disabilities, 2017; Anderson & Pettingell, 2023) describe a widespread shortage of staff. The National Core Indicators workforce report (2022) reveals the average turnover rate for DSPs is 43 percent, average vacancy rate is 15 percent and average hourly wage is $14.50 (below jobs in retail, warehouse and food service). Adjusted for inflation, wages nationally are lower now than 10 years ago.

To correct the institutional legacy of community services, the Medicaid "Settings Rule," implemented in 2023, cut funding for housing and workplaces that isolate individuals from the public. It requires individualized support and social integration. These services are more staff-intensive than institutional care—but no additional resources are allocated to improve staff levels (Medicaid, 2014).

The workforce shortage has multiple causes (Hewitt et al., 2018b; President's Committee for People with Intellectual Disabilities, 2017, pp. 26-32). One is low pay and poor benefits. Average DSP wages fall below the federal poverty level; half of DSPs rely on

government-funded benefits and most work multiple jobs. Another is limited credentialing and career pathways. A lack of occupational recognition means that DSPs have little earning potential. Third is a shift in the type of services delivered. The role of DSPs has evolved from providing custodial care to giving coaching support—working with people to enable quality of life outcomes. Special education trains individuals with fewer challenges to live in a semi-independent manner, leaving adults with more challenges, who are harder to serve, clustered in staffed group homes and day centers.

Staff shortages negatively impact families (who must constantly advocate to ensure their loved one receives needed support). Staff shortages damage agencies (which make substantial overtime payments and waste resources continually replacing staff). Staff shortages hurt DSPs (many of whom work overtime or multiple jobs, causing burnout and adding to turnover and vacancies). Staff shortages harm service-users (who do not receive the person-centered support and community integration to which they are entitled by law). Because of inadequate staff, 92 percent of agencies are struggling to manage existing services and achieve quality standards. Sixty-three percent have discontinued programs and discharged individuals and 55 percent are considering further service cuts. Eighty-three percent are refusing new referrals—nationwide, 473,000 people remain on wait lists (American Network of Community Options and Resources, 2022; United Cerebral Palsy, 2020, p. 14).

Addressing the staffing shortage requires paying competitive wages and creating competency-based career ladders (American Network of Community Options and Resources, 2022; Hewitt et al., 2018c; President's Committee for People with Intellectual Disabilities, 2017, pp. 33-41). These measures cannot happen without generous funding. Most IDD

services are paid for by Medicaid, a joint federal-state finance arrangement. Unlike businesses, agencies cannot raise the price of services to pay staff more. Non-negotiable wage rates are set by state legislatures, and because of inadequate reimbursement, agencies cannot be competitive employers.

The Illinois Staffing Shortage

The 1990 Americans with Disabilities Act's (ADA) "Integration Mandate" requires that services be provided in the most integrated setting appropriate to a person's needs. Many states disregarded this demand. The state of Georgia was sued, and the 1999 Supreme Court ruling in Olmstead v. L.C. (1999) declared that unjustified segregation constitutes discrimination and directed states to provide suitably-funded services in community settings. Illinois continued to ignore ADA and Olmstead integration mandates, so lawsuits were brought by people with IDD living in segregated facilities (Illinois Department of Human Services, n.d.). Following the 2011 Illinois Ligas v. Hamos settlement, thousands of individuals—including David—moved into the community. The consent decree requires adequate resources to ensure services that support person-centered inclusion, but Illinois has deprived agencies of necessary funds. Staff turnover is 42 percent, vacancy rates are 16 percent and average hourly wage is $16.24 (National Core Indicators, 2022, pp. 22, 24 and 34). Staff shortages hinder community participation—many individuals have limited outings and spend time in sheltered activity centers and group homes. Staff shortages also compromise person-centered care. High turnover makes it difficult for inexperienced DSPs to implement service-users' personal goals, maintain their skills, and build independence.

One response has been litigation. In 2017, disability rights groups filed a motion arguing that poor care resulting from low reimbursement violated the Ligas settlement. The

court ordered an update of the state's payment methodology. The 2020 Guidehouse Plan provided a roadmap to stabilize community services—but the legislature refuses to fully fund its recommendations (Illinois Department of Human Services, n.d.). A second response has been advocacy. In 2017, a coalition of families, service agencies, and advocacy organizations formed *They Deserve More* to increase state funding. Despite incremental investments, DSP pay has not kept pace with minimum wage increases, inflation, the competitive job market, or the actual cost of delivering services (They Deserve More, n.d.).

Staffing Shortage Summary

There are no services without a qualified and reliable workforce. Support from knowledgeable and familiar staff is necessary for individuals with IDD to achieve integrated and individualized lives. Staff shortages occur because agencies are not reimbursed enough to offer competitive wages and career pathways. Turnover and vacancies create an unstable environment for both service-users (whose needs cannot be met by inexperienced staff) and DSPs (who have increased stress from working overtime at several jobs).

Philosophical Analysis

In developed nations, service agencies face significant challenges recruiting and retaining staff, with adverse outcomes to people with IDD. I now use philosophical concepts to analyze each element of the *They Deserve More* motto—who is the *they*, what does it mean to *deserve* and what is the *more*.

They Deserve More

The *they* who deserve more is both people with IDD and the DSPs who support them. As Kittay (1999) points out, the interests of care-receivers and of care-givers are intertwined. David's prenatal brain injury adversely impacts his functioning in every area. He does not

read, is nonverbal, cannot understand significant choices, and needs assistance with all activities of daily living. Because David requires support from DSPs, caring for him is inseparable from caring for them. To deny them a living wage and feasible career path (resulting in high turnover and vacancy rates) is *eo ipso*—and as an inevitable result—to deny him quality care.

The intertwining of care-receiver and care-giver needs entails what Kittay (1999) calls the *doulia* principle. A *doula* is the postpartum caregiver who cares for a mother so that she can care for her infant. In a public conception, the *doulia* relation concerns social support: as the *doula* cares for the mother who cares for the newborn, so society should care for DSPs MacKenzie and Carl through generous compensation so they can care for David. The *doulia* principle "links those who need help to those who help, and links the helpers to a set of supports .... Just as the caregiver has a responsibility to care for the dependent, the larger society has an obligation to attend to the well-being of the caregiver. Only so can the caregiver fulfill responsibilities to the dependent" (Kittay, 1999, pp. 132-133).

There are two levels of obligation in caring for David—the personal obligation of his DSPs and the social obligation to his DSPs. These duties cannot be separated since care for David is constituted by care for his caregivers. Society has care for people with IDD as a necessary obligation—and since care for them requires DSPs who provide that support, a just society also has care for DSPs as a necessary obligation.

Society must support DSPs so they can support people with IDD. But MacKenzie and Carl deserve to be treated fairly for their own sakes, not simply because it will benefit David. DSPs are subjects of moral consideration apart from their usefulness as a means to some other end (i.e., care for disabled people). Society has direct duties *to* them, not indirect duties

concerning them (Regan, 1986, pp. 180-181). Suppose I consider smashing your car's windshield. My indirect duty to not damage your car is not owed to the car but is simply a direct duty to you. Now suppose I think about kicking your dog. Here I have both a direct duty to the dog (not to hurt it) and a direct duty to you (not to upset you). DSPs do not only indirectly deserve good treatment because society has a direct duty to adults with IDD. They have intrinsic, not just instrumental, value. DSPs deserve good treatment directly, not derivatively.

Many frontline staff are racialized women. In the United States, 89 percent of DSPs are women, and 50 percent are people of color. Women of color are the largest and fastest growing segment of the workforce (Campbell, 2017). In Europe, too, there is gender imbalance—82 percent of the social service workforce is female (European Public Service Union & Federation of European Social Employers, 2020, p. 4). Many have limited education and few employment options, but DSP jobs do not provide economic stability. Women caregivers—especially women of color—are more likely to live in poverty and rely on public benefits. As care needs grow, more countries are relying on migrant workers (Anderson, 2012). In addition to being an economic justice issue, underpaying DSPs is a gender and race justice issue.[4]

They Deserve More (n.d.) puts it well: "It is time to make a stand for Illinoisans with developmental disabilities and those who serve them. They both deserve more."

They <u>Deserve</u> More

People with IDD and DSPs *deserve* more. In common usage, the word "deserve" has a narrow meaning that is nearly interchangeable with "earn." What someone deserves is based on past choices and actions for which they are responsible. Students deserve—they

earn—grades by their academic performance (Schmidtz, 2006, chapter 9). But I am using the term in a broad philosophical sense that covers all forms of distribution.[5] In this understanding, to deserve is to merit, be worthy of, or have a claim to something (either reward or punishment, merit, or demerit). What someone deserves can be based on their actions, but also on their qualities or situation (Oxford English Dictionary, n.d.). A drowning child deserves to be rescued—this benefit is unearned but deserved. The philosophical definition of "desert" (referring to what a person deserves, as in common usage such as "he got his just deserts") is part of a group of closely related concepts: rights, entitlement, justice, and obligation.

First, desert involves *rights*. A right is a justified claim to be treated in a certain way. Rights impose duties on others. Rights are more than favors that depend on sympathy and may be given or withheld at will—they are owed and must be respected. Rights are both negative (to not be harmed) and positive (to be helped)—they can be violated both by causing injustice and refusing to correct it.

Second, desert is related to *entitlement*. To be entitled to something is to have a proper claim to it. Fred Feldman and Brian Skow (2015) suggest that the concepts are not identical: desert is prescriptive and moral while entitlement is descriptive and legal. Entitlements exist when institutional rules establish the conditions under which someone should receive something—the ADA, for example, grants people with IDD the legal right to community living. There can, however, be entitlement without institutional acknowledgment. People with IDD were morally entitled to inclusion before the ADA legally required it—and DSPs are morally entitled to, though not politically granted, a living wage. Legislation and litigation are necessary to convert moral entitlements into legal entitlements.

Third, desert concerns *justice*. Justice—giving people what they are due—differs from benevolence. Joel Feinberg (1980a, p. 142) identifies two kinds of moral transactions. "On the one hand, there are gifts ... and favors motivated by love or pity or mercy and for which gratitude is the sole fitting response. On the other hand, there are dutiful actions and omissions called for by ... rights .... . These can be demanded, claimed, insisted upon." Charity is optional—justice is required.

Finally, desert is connected with *obligation*. Obligatory actions are mandatory—they must be done whether a person or institution wants to or not. Supererogatory actions are discretionary—while good to do, they are not required. Unlike elective gratuities, deserved treatment is called for by rights that impose duties which must be performed.

The conceptual structure of desert has four elements: (1) a deserving subject—a person who deserves something; (2) a deserved object—a mode of treatment the subject deserves to receive; (3) a desert basis—facts about the subject because of which they deserve the object; (4) a desert source—the person or institution from whom the subject deserves the object. The four-part relation between subject, object, basis, and source can be expressed in the formula: person A deserves item X from person or institution B because of feature Y (Feldman & Skow, 2015).

These four elements apply to disability policy. The deserving *subjects* are people with IDD and the DSPs who support them. The deserved *object* is well-staffed, person-centered, integrated services for people with IDD and adequate wages and career paths for DSPs. The desert *bases* are inherent qualities of people with IDD and voluntary actions of DSPs. The desert *source* is the state—government must provide the financial resources necessary for adults with IDD and DSPs to achieve well-being. Desert ranges from weak to strong

depending on its importance. The strong desert of people with IDD is based on essential

needs they have. The strong desert of DSPs is based on the complex and vital work they do.

The Desert Bases

Two distinct considerations constitute the desert *bases* for what people are owed

(Darwall, 1992). One is performing certain actions. This is what earning is—deserving to get

something in return for an action. Students earn grades by their learning. Personal desert is

based on what we do, on effort and achievement. The other is possessing certain attributes. A

drowning child deserves to be rescued; this benefit is unearned—and yet the child deserves it.

Human desert is based on what we are, on worth and needs.

Why DSPs Deserve More

Like the student deserving high grades, DSPs deserve generous wages as a matter of

personal desert. They have a right, Kittay (2001) says, to "compensation that matches the

intensity of their labor" (p. 573). But the President's Committee for People with Intellectual

Disabilities (2017) points out "there is a significant discrepancy between the job

responsibilities and skill expectations of DSPs and their low wages" (p. 55). Staff roles are

evolving from caretaking to coaching—DSPs are expected not to do things for people but to

teach and help them do things for themselves. Supporting is more demanding than

caregiving; it requires a workforce with diverse skills.

Stephen Nathanson (1998) identifies three criteria for determining what a person

deserves as fair pay: "their effort (how hard they work), their achievement (the value of the

results of their work) and their abilities (the level of skill that is required to do their work)"

(p. 56).

In terms of *effort*, DSPs work long hours. Because of turnover and vacancies, many

do overtime or have multiple jobs. The work is difficult and demanding. As Amy Hewitt and colleagues (2018a) point out, "DSPs are generalists who have to be able to provide whatever support is needed across a wide range of activities throughout the lifespan of people with IDD" (p. 6). In David's home, staff juggle the needs of four men simultaneously—preparing meals, dispensing medications, and helping them make beds, wash laundry, perform hygiene activities, and access the community.

In terms of *achievement*, support work is vitally important. "E**ssential workers"** conduct a range of services necessary to the continuity of critical social functions. Like employees in healthcare, food service, and public safety, DSPs perform essential services that can never shut down. Robert Curriden (2018) describes his work providing behavioral support, supporting activities of daily living and independence, "administering complex medications, and providing medically necessary routines and interventions" (p. 14). DSPs have immense responsibility—their work is essential to the health, safety, and well-being of those in their care.

In terms of *abilities*, DSPs perform challenging and sophisticated work. As Hewitt and colleagues (2018a) state, "the direct support job is highly complex and requires sound judgment and significant skills that include independent problem-solving, decision-making, behavioral assessment, crisis prevention and intervention, and communication. Many DSPs are often isolated, without co-workers, supervisors or clinical professionals on-site to provide assistance or guidance" (p. 4). They are multidisciplinary experts: like teachers they impart skills, like nurses they dispense medications and treatments, like social workers they access community resources, like counselors they listen and advise. DSP competencies include communicating, providing person-centered support, community networking, facilitating

living skills, advocating, vocational assistance, crisis intervention, documentation, enabling physical and emotional health and wellness, and helping service-users build relationships. Support work demands dedication and commitment as well as knowledge, skill, and compassion (National Alliance for Direct Support Professionals, n.d.).

DSP are essential workers, professionals performing expert work—they deserve pay that aligns with the critical nature of the job. Compensation should at least be a living wage. It should also be tied to certification—as DSPs achieve additional qualifications, their pay should increase. They deserve more as a matter of earned, personal desert.

Why People with IDD Deserve More

Like the toddler deserving rescue, people with IDD deserve quality support as a matter of human desert.[6] Many rely on DSPs for what Feinberg (1980b) calls "basic instrumental goods of life—food, shelter, protection," needs that create "dependency rights" , (p. 126). David wants what everyone else wants—a happy life. Flourishing consists in a bundle of basic goods given in human nature; a person's life goes better if it includes more of them and worse if it has fewer.

Robert Schalock and Miguel Verdugo Alonso (2004) identify eight domains of a good life: physical well-being, mental well-being, personal development, social relations, participation, self-determination, material well-being, and rights. The Council on Quality and Leadership's *Personal Outcome Measures* (n.d.) organizes quality of life around five domains: security (being safe, free from abuse and neglect), community (living in integrated environments, participating in social life), relationships (having friends and intimate partners), choices (selecting where and with whom to live, work, and spend daytime hours) and goals (choosing and achieving personal wishes). These are substantive components of

human well-being.[7] People with IDD need to have their safety ensured, be healthy physically and emotionally, engage in activities they like and can do well, enjoy social relationships, be trained in their best competencies and experience a sense of contentment. If life can be good when these key dimensions are present, it can also be bad when they are missing.

People with IDD have deficits in intellectual and adaptive functioning. David has limited skills of self-management—communicating, solving problems, exercising good judgment, setting goals, and completing tasks. Without stable DSP support, adults like him cannot flourish. Instead of being healthy physically and settled emotionally, they become sedentary and distressed. Instead of performing meaningful activities, they spend their time in dull, repetitive tasks that leave them idle and disengaged. Instead of enjoying strong relationships, they are isolated and lonely. Instead of being trained to maximize their abilities, their personal development is stunted. Instead of having a sense of well-being, they experience a flat, one-dimensional life.

Individualized attention and social inclusion are not possible when disabled people receive poor support from overworked staff or a constant turnover of inexperienced DSPs. People with IDD deserve consistent and competent staffing for vocational and residential programs—and adequate funding that upholds them—as a matter of basic, human desert.

The Desert Source

The desert *source* from whom people with IDD and DSPs deserve assistance is the state. The reasoning is disjunctive. People with IDD have basic needs and quality of life needs that must be met for them to enjoy a decent level of well-being. These needs cannot be met by the person themselves. Like David, many cannot care for themselves because of difficulty thinking, planning, choosing, and communicating. The needs of people with IDD

cannot be met by family and friends. Some families provide care because they choose to, but others do so because they must (since group home placements are hard to get).[8] Families who place their loved one out of home trust service agencies, not themselves, to provide care. The needs of disabled people cannot be met by voluntary community altruism. Charitable giving in the United States is about two percent of income annually, and much of that goes to arts programs, educational institutions, and religious organizations, not social care agencies. Individuals with IDD cannot rely on neighbors, faith communities, or service clubs to look after their needs (Singer, 2009, pp. 23-24). Therefore, the only option is that their needs be met through tax-funded government services. A parallel argument applies to DSPs, whose work cannot be financed through private charities or agency grant-writing and fundraising, but only by generous public reimbursement.

Recall the desert formula: A deserves X from B because of Y. DSPs deserve adequate compensation from government because of their complex and indispensable work. People with IDD deserve generously funded services from the state because of their inherent worth and vital interests.

They Deserve _More_

People with IDD and their support workers deserve *more*. The government support that they deserve is either less than, the same as, or more than they already receive. To give them less will make their quality of life worse than it is now. To give them the same will perpetuate the current situation (described earlier), leaving disabled people without essential services and DSPs without adequate compensation. As I have previously discussed, only if they are given more will both groups thrive rather than survive (Gould, 2021a; 2021b).

Viable political theories hold that wealthy societies should guarantee all members a satisfactory standard of living—in particular, they should help people meet significant needs they cannot meet on their own. A social minimum, Stuart White (2015) says, is "the bundle of resources that a person needs in order to lead a minimally decent life" ("What is Social Minimum?", para. 1). A just society enacts "institutions and policies that secures every member reasonable access to a social minimum" ("What is Social Minimum?", para. 1). This is the deserved object.

The *content* of a social minimum can be defined in terms of needs. Needs are essential conditions that must be met if a person is not to suffer harm. Welfare interests (like physical health and financial resources) are the necessary means to higher goals (like playing an instrument or managing a restaurant). When these basic needs are not met, a person's entire set of interests is damaged. As Feinberg (1984) says, "welfare interests most certainly are grounds for moral claims against others" (p. 112). Gillian Brock and David Miller (2024) agree that needs carry moral weight. "The needs that matter ..., especially in political distribution, are those that are necessary, indispensable and inescapable, given the kinds of creatures that we are and the requirements for functioning in social settings" ("Common Strategies for Responding to such Strategies," para. 1). Further, a "person's being in need always counts as a strong ... reason to aid them" ("Needs and Capabilities," para. 3). Because the harm David and his DSPs experience suffer when their needs are not met is serious, they are a matter of political priority.

The *content* of a social minimum can also be defined in terms of capabilities. Martha Nussbaum (2006) identifies capabilities as central human functions such as physical and emotional health, social interaction, meaningful work, engaging play, and control over one's

environment. Because the core capabilities are necessary for living well, they ground political entitlements to what is necessary for their fulfillment. These deserts "should be respected and implemented ... as a bare minimum of what respect for human dignity requires" (pp. 76–78). If a capability is not adequately satisfied, then society denies that person the opportunity to lead a good life.

The *amount* of a social minimum can be defined by two broad standards (Nathanson, 1998, chapter 9). A bare minimum is meager assistance that simply prevents severe harm. It does not make people well off—while avoiding the worst, it still leaves them badly off. A comprehensive minimum is generous assistance that provides the resources necessary for a good quality of life. Harry Frankfurt (2015) states that when establishing a social minimum, each person should have enough:

> Having enough money [or other resources] is far from being equivalent to having just enough to get by, or to having enough to make life marginally tolerable .... The point of the doctrine of sufficiency is not ... whether people have enough to avoid ... misery. A person who [has] just barely enough does not really ... have enough at all. (p. 49).

Disabled adults and DSPs deserve a generous social minimum. The notion of a decent level of well-being is vague, but not hopelessly vague (White, 2015). First, the end is identified—the needs that are essential for a good quality life. Second, the means are determined—the kind and level of resources that are necessary to adequately meet those needs. The goal for DSPs is a living wage and professional credentialing—the means is generous state funding. The goal for people with IDD is high quality vocational and residential programs that are integrated and individualized—the means is stable staff and ample funding to pay them. The first cannot happen without the second. Without adequate

compensation, DSPs will underperform, burn out, and leave for easier jobs with better pay. Without competent support, disabled adults will remain in facilities that isolate them, do little to develop their abilities, and stifle their fulfillment.

What DSPs Deserve

DSPs need sufficient income to purchase food, housing, household necessities, transportation, healthcare, and childcare. They need economic security so they do not struggle to cover these payments. They need a predictable 40-hour work week so their jobs do not take a toll on personal health, close relationships, and leisure activities. But many lack the financial resources necessary to support themselves and their families. They experience "secondary dependency" (Kittay, 1999, p. 46). The American Network of Community Options and Resources (2017) points out the paradox: "those who are caring for individuals on [public assistance] need public assistance themselves to make ends meet" (p. 12). In addition to a living wage, DSPs deserve affordable benefits: health insurance, paid time off, childcare subsidies, and retirement plans. Because the workforce is comprised largely of women of color, generous compensation, and career opportunities are matters of gender and race equity.

DSPs also deserve career advancement through competency-based credentialing that professionalizes their work. In addition to poor wages and benefits, inadequate preparation and career development opportunities contribute to the staffing challenge. The President's Committee for People with Intellectual Disabilities (2017) acknowledges the "failure to create an occupation of DSP with sufficient pay, benefits, training and career trajectories and status to recruit and retain a stable, skilled workforce" (p. 26). The issue is not just how they are paid, but how DSPs are developed and promoted. In 1996, the National Alliance for

Direct Support Professionals (2011; 2019) created a multi-level certification program based on core competencies—the knowledge, skills, and attitudes needed for high quality support. Credentialing provides a career path with wage incentives and recognition of DSP work as a professional career, not a low-skill, temporary job. Provider agencies and community colleges in multiple states have established certificate and mentoring programs. Competency training and standardized credentialing decrease turnover rates, but education and certification remain voluntary and are not widely utilized (Bogenschutz et al., 2015; Kramme, 2018). The Recognizing the Role of Direct Support Professionals Act was recently introduced in Congress. It would have revised the federal Standard Occupational Classification system to establish a separate code for DSPs and would have created better understanding of the labor market shortage and high turnover rates. The legislation did not pass (Congress, 2023).

The means of meeting DSP needs is generous funding for wages and benefits, training, and certification. Poverty-level pay is the primary reason many leave employment. The American Network of Community Options and Resources (2017) asserts that "low wages occur because agencies are constrained by low, non-negotiable reimbursement rates set by their states' Medicaid agencies .... This difficult situation must be remedied by state legislatures and the federal government by prioritizing increased Medicaid rates to IDD services" (pp. 12–13). The same is true internationally: as the European Association of Service Providers for Persons with Disabilities (2019) says "the single biggest solution to staff shortages ... is to ensure that the sector is adequately resourced by public funding" (p. 12).

What People with IDD Deserve

Limited executive and adaptive behavior impact the health and wellness, community involvement, social relationships, and employment of disabled adults. David cannot meet his own *basic living needs*. He cannot wash himself clean if he loses bowel control; he cannot care for himself when sick; he cannot prepare food without assistance; he may not choose weather-appropriate clothes; he cannot effectively perform oral hygiene. Nor can David meet his own *quality of life needs*. Without staff support, he would sit around all day playing computer games rather than interacting with other people, engaging in work or recreation, and participating in the larger community. Like him, many people with IDD depend on DSPs for everything: preparing food, bathing, managing social situations, healthcare visits, transportation, and jobs.

To meet their needs, people with IDD require high quality vocational and residential programs that are well-staffed. Yet many are harmed by inadequate services due primarily to inconsistent staffing. Individualized attention and community inclusion are not possible when they receive deficient support from overworked or inexperienced DSPs. The results are social isolation, a lack of productive activities, limited skill development, and increased anxiety, depression, and aggression (Wolf, 2017).

The means of meeting disabled people's needs is generous resources for vocational and residential services. In particular, agencies must receive ample funding to hire, train, and retain DSPs long-term. The American Network of Community Options and Resources (2017, p. 16) advocates indexing pay to minimum wage levels or the Consumer Price Index and setting rates based on actual costs incurred by agencies. In Illinois, the Guidehouse Plan recommends a DSP wage at least 150 percent of the minimum wage. The legislature refuses

to fund this amount, and recent expenditure increases do not compensate for decades of underinvestment.

Nussbaum (2010) reminds us that "people are entitled not only to mere life but to a life compatible with human dignity, and this means that the relevant goods must be available at a sufficiently high level" (p. 79). DSPs deserve compensation that does more than prevent poverty, which it often fails to do. They deserve to support themselves comfortably without working overtime, taking multiple jobs or relying on government benefits. They deserve a living wage and open career paths. People with IDD deserve services that do more than prevent harm but leave them missing out on many things necessary to a full life. They deserve continuity of support, rather than instability because of staff turnover and vacancies. They deserve person-centered and community-integrated services—legal entitlements that cannot be met without sufficient staff.

Conclusion

A few months ago, I received this email from the supervisor of David's group home: "[Worker A] resigned last night three hours before her scheduled shift. [Worker B] stayed until 10 p.m. and [worker C] came in last minute for the overnight. The guys were concerned about where [worker A] was. I will do my best to fill her shifts with staff the guys know, but this will be an adjustment for them." The churn of DSPs, especially in stressful locations with high service needs, is common. Hewitt and colleagues (2018a) summarize:

> [T]he health, safety and well-being of people with IDD is at risk daily because of the workforce problems. A revolving door of strangers coming in and out of a person's life, often required to support in the most intimate personal care routines, means that far too often they may not trust or develop a meaningful professional

relationship with the DSP. Signs and symptoms of illness are missed, opportunities for community participation are lost, and people with an IDD have few choices other than congregate models, such as group homes or sheltered work settings, because community staffing is unstable. (p. 7).

Decreased service quality results from inadequate staffing, which results from insufficient funding.

Let me again make clear that I am not blaming service agencies or DSPs. Instead, I am criticizing the public disability system that does not provide economic stability to DSPs or suitable programs to people with IDD. These pervasive deficiencies have persisted for decades. The failure, Hewitt and colleagues (2018a) assert, is rooted in "a fundamental lack of respect for people with disabilities and the staff who choose careers in providing support to them" (p. 3). Society, Curriden (2018) adds, is:

> [C]aring for ... the weakest and most vulnerable ... through abusing the good will of DSPs who work two and three jobs; who must have public assistance to feed their families ... ; and who willingly work holidays, weekends, and sixteen-hour double shifts .... In so doing, we are abusing those individuals that we, as a society, have an obligation to provide for and protect. (p. 14).

By violating the *doulia* principle, public disability systems mistreat both support workers and service-users.

People with IDD and DSPs deserve more on a *naturalist* theory of justice, because they possess human rights grounded in inherent human worth, vital human interests, and vital work. People with IDD (and, by extension, DSPs) also deserve more on a *conventionalist* theory of justice, because they possess legal rights established by civil legislation and court

rulings. The ADA and Olmstead ruling give disabled people the right to personalized participation in the major spheres of life and the financial support required to realize their potential. Similar legal entitlements exist in other jurisdictions. A stable workforce is necessary for states to comply with integration mandates. People with IDD will not have quality residential and vocational services until the staffing crisis is resolved through better wages and professional recognition. As Carli Friedman (2018) says: "DSP continuity is central to quality of life of people, including human security, community, relationships, choice and goals. States cannot continue to provide near-poverty level reimbursement rates for DSPs and still ensure quality of life" for adults with IDD and their support staff (p. 234).

Government budgets are moral documents that do not simply concern economics but indicate national values. There are real human persons attached to legislative appropriations and budget numbers (Smith, 2023, p. 20). Generous funding that addresses the staffing shortage through wage stabilization and career professionalization is not an optional gratuity but a duty owed as a matter of justice. *They* (people with IDD and DSPs) *deserve* (as an entitlement, not a favor) *more* (plentiful resources from a wealthy nation).

At this moment in the United States, however, there appears to be little hope for these positive changes. Instead, the second Trump administration is inflicting havoc on Americans and threatening dire consequences to adults with IDD. Republican legislators plan to substantially reduce Medicaid funding, cutting hundreds of billions of dollars to offset tax cuts for wealthy individuals and profitable corporations (Orris & Zhang, 2025). The Administration for Community Living—a federal agency supporting independence for people with disabilities through accessible transportation, alternatives to guardianship, respite care, improving home and community-based services, and enhancing the direct care workforce—is

being dismantled through funding cuts, mass firings, and program closures (Diament, 2025). In Illinois, the governor's proposed 2026 budget adds $20 million in wage increases for DSPs—but also cuts $32 million in staffed support hours (which will force agencies to eliminate vital frontline positions and threaten essential care for individuals in group homes). This reduction in services will harm people in the system much more than the wage increase will help (They Deserve More, 2025). As I have noted before, in the face of these challenges, adults with IDD and their allies must remain hopeful and motivated to concrete social justice activism (Gould, 2024). Because they deserve more!

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Footnotes

[1] In other countries, "DSP" stands for "Disability Support Personnel."

[2] Traditional services pay nonprofit agencies to operate residential and vocational programs, while self-directed services provide personal budgets allowing individuals to live at home, design their own service plans and hire support staff. In the United States, the residence for most adults with IDD—61 percent—is their family home (Residential Information Systems Project, 2021).

[3] A similar anecdote—of Hugo, a disabled young man in Finland—is related in Vehmas & Mietola, 2021, pp. 116-118.

[4] Nadasen (2023) argues that today's care economy—which includes DSPs—exploits low-wage workers, immigrants, and women of color.

[5] The contrast between desert as a *distributive principle* for assigning goods to individuals and desert as a *corrective principle* that requires remedy when one person wrongs another goes back to Aristotle (Miller, 2021).

[6] I am not equating people with IDD to toddlers but am referencing the earlier example of rescuing a drowning child as something unearned but deserved.

[7] These approaches correlate with positive psychology models, from Maslow (1970) to Seligman (2011).

[8] Family members who provide care spend, on average, 57 hours each week in a support role. Many family carers are aging: 24 percent are over age 60. Caregiving is hard work that creates practical, psychological, and financial stress—especially for women, who provide the most care (Braddock et al., 2017; Anderson et al., 2018).

Book Review

Disability Rights and Justice: An International and Collective Issue

Review of *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*

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Editor's Note:

Although this book was published five years ago and has been cited in subsequent scholarship in the journal, a formal review has not previously appeared in the *Review of Disability Studies*. We are honored to present this review by LuanJiao (Aggie) Hu.

Abstract

This book review discusses *Being Heumann*, Judy Heumann's memoir highlighting her lifelong advocacy for disability rights. It details her personal struggles and successes, reflecting broader societal issues of ableism. The reviewer emphasizes the memoir's significance for understanding disability activism, noting its global relevance and inspirational value for international disability advocates.

Keywords: Judy Heumann, disability rights, disability activism

Disability Rights and Justice: An International and Collective Issue

Review of *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*

For anyone interested in knowing more about disability rights movement in the United States or about the triumphs and struggles of a disabled woman leader, the 2020 book *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist* by the late Judith (Judy) Heumann and Kristen Joiner is a must-read. Divided into three parts based on Heumann's life trajectory, the book offers a panoramic view of Heumann's life as a disabled white woman, a polio survivor, a wheelchair user, and a lifelong disability rights activist.

From reading major life events and personal reflections of Heumann, one can get an intimate insider perspective of what it is like to live with a disability in the United States since the 1950s, the struggles and vulnerabilities a disabled woman feel in the face of prevailing ableism, and what the journey looks like to be one of the pioneers in the disability rights movement. Spanning seven decades in Heumann's timeline and covering different milestones in major disability legislation in the United States, the book also provides readers a closer look at how the disability advocacy landscape came to its present form in this country.

Judy Heumann was perhaps the most renowned disability activist domestically and internationally until her death on March 4, 2023. The book can be an introductory but compelling read for anyone who wants to increase their understanding of the disability experience and disability resistance in a dominantly non-disabled world. For individuals with disabilities, Heumann's book will be highly relatable and powerful, as Heumann shared her educational experiences in both segregated and mainstream school settings, the exclusive and

discriminatory treatment she had received as a disabled girl and woman navigating different spaces, the advocacy endeavors engaged by her family, herself, and later the greater disability community, and her empowering journey in disability activism and community organization. For any international readers, Heumann's life story as an American disabled female activist can offer great insights and thought-provoking materials for comparative reflections on disability oppression and empowerment in transnational contexts. As a woman with a physical disability originally from China, I found this 175-page book highly accessible and relatable. As an international disability activist and scholar, I found Heumann's story and many of her reflections resonated with me. I am equally grateful that Heumann developed a strong voice and acquired opportunities to document her journey on multiple platforms. Before her passing, Heumann announced on her Twitter account that her book had been translated into Japanese.

Heumann's struggles as a disabled woman are not unique to herself. Numerous disabled people around the world today still find themselves encountering similar hurdles that Heumann detailed in her book. Globally, disabled people face seemingly insurmountable obstacles to accessing education, employment, recognition, and participation in various aspects of societal life. Sadly still, as most people with disabilities in the world reside in developing countries, a significant population does not have the privilege of living in a more developed country and having access to the opportunities or resources that Heumann had, including crucial access to education.

Heumann wrote in her book that children with disabilities in her time (1960s) were not expected to progress up the ladders of education. She initially had a hard time gaining the education that her peers without disabilities took for granted. Luckily, before Heumann

became a fierce advocate herself, her parents served as solid advocates from her immediate support system. They fought fearlessly to get her access to education and inclusion in local schools. This was utterly important. Gaining access to quality education is crucial for persons with disabilities. It is the first step to break marginalization for historically disadvantaged populations and has the great potential of catalyzing greater social inclusion. Equally important for persons with disabilities is the presence of advocates. Given the magnitude of barriers presented in disabled persons' lives, they either grow into advocates for themselves, or have others ready to speak for their case in circumstances of exclusion.

Heumann was one of the few disabled persons who succeeded in their major advocacy fights. "With a different judge, my court case could have gone completely differently," Heumann wrote, reflecting on her fight to get a teaching license by suing the New York City Board of Education. Heumann admitted that she was fortunate to have had Constance Baker Motley, the first black female judge in U.S. history, preside over her case against the Board of Education. Successful cases such as Heumann's have not been common. It takes individual determination and resources (the power and ability to fight back), collective wisdom (allies to organize and strategize in the fight), contextual support (increased rights-based awareness in the backdrop of the civil rights movement), as well as luck (the right judge who understood profoundly what discrimination meant).

Unfortunately, we more often hear and see cases of continuing discrimination and perpetual exclusion. In China, where I come from, disabled people still struggle in fights similar to Heumann's in the 1970s. In 2021, a female wheelchair user in China was denied a teaching license simply based on her disability. This came despite ranking in the top in written and oral exams, having many years of teaching experience, and holding two master's

degrees (China Labour Bulletin, 2021). Another veteran Chinese teacher was denied an official teaching license because of her use of a prosthetic eye. The veteran teacher, undefeated and determined, engaged in multiple court cases against the local bureau of education. After four years of court trials, the teacher with a prosthetic eye finally won her case and received her teaching license in 2020 (Shi, 2020). Nonetheless, no local schools were willing to hire her, largely given her confrontational history with the local educational bureau. These discriminatory encounters have been obstructing people's access to opportunities and resources and forcing disabled people to develop strategies to fight back. The outcomes have not always been successful. At times, encounters of this sort take a further toll on the health conditions of people with disabilities.

Heumann's book is one of the volumes on disability written by people with disabilities. In recent years, disability community leaders in the United States, such as Alice Wong, Haben Girma, and Emily Ladau have published edited volumes or monographs to advocate for and/or amplify the voices of the disability community. This is a continuation of the writings by persons with disabilities since the 1980s. In the U.S., among other educational, political, economic, and legislative development, including passage of the Americans with Disabilities Act in 1990, disability studies as an academic discipline also emerged. With its growth since the 1990s, disability studies contributed to the increasing influence of disability research and documented lived experiences. Popular publications such as Heumann's book constitute an important force in the disability rights movement. Since ableism remains deeply embedded in societies across ideologies and countries, collective action is urgently needed to dismantle it. Drawing from her experience in resisting

ableism, Heumann wrote: "All I knew was that we would have no power at all if we weren't united" (Heumann & Joiner, 2020, p. 104). She further observed:

> Change never happens at the pace we think it should. It happens over years of people joining together, strategizing, sharing, and pulling all the levers they possibly can. Gradually, excruciatingly slowly, things start to happen, and then suddenly, seemingly out of the blue, something will tip. (Heumann & Joiner, 2020, p. 145).

It is an international and collective issue for us to advance disability rights and justice. I see the value of introducing Heumann's book to an international audience that is interested in advancing disability causes elsewhere. Heumann's activism and determination in promoting disability justice have the potential to inspire hope, strategies, materials, and comparative reflections for activists and organizers beyond the U.S. border.

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Media Review

A Troubling Place:

Disability and *A Quiet Place: Day One* (2025), A Review

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Abstract

This review of the latest edition of the popular franchise praises the film for its compelling performances and narrative while bringing attention to its troubling ableist fantasy of a future without disabled people.

Keywords: film, representation, disability, horror, science fiction, ableism

A Troubling Place:

Disability and *A Quiet Place: Day One* (2025), A Review

Figure 1. *Image of Lupita Nyong'o (Sam) looking towards the sky and holding a cat in a Quiet Place: Day One*

  A Quiet Place: Day One is a relentless, epic journey that thrusts us back to the origins of the franchise's terrifying silence. It's intense, beautifully shot, and gripping. But for those of us who think about disability and representation in film, it's also a deeply frustrating ride — offensive in a way that feels so familiar it's almost comforting. The first two *A Quiet Place* films were praised for their disability consciousness, particularly through the inclusion of deaf actress Millicent Simmonds and a narrative that appeared to invite a non-deficit model of disability (as I suggested in [RDS Vol 15, No 1](#).) This film is different.

  The film follows a formula we've seen countless times before. Disabled characters, directly or indirectly, hold society back — or so the narrative implies. And as the story

reassures us, it's okay, because they would rather die anyway. It's a trope that runs through cinema history, from *The Elephant Man* to *Million Dollar Baby*, where disabled lives are framed as tragic burdens rather than complex, valuable existences. The third installment of this franchise continues this legacy of minimizing the lives of people with disabilities in a way that feels particularly pointed.

Set in New York City on the day the alien invasion begins, the story features giant, sound-hunting monsters that decimate the noisy while sparing the silent who can hide their pain. Our heroine, Sam (see Figure 1) played by the exceptional Lupita Nyong'o, is a jaded cancer survivor navigating her world with resilience and small comforts like her cat and her memories — especially of pizza. Nyong'o's performance is remarkable, and her character's quiet strength is compelling. But as the story unfolds, it becomes clear that her fate is sealed from the start.

In her final act alive (***major spoiler alert***), knowing that sound will summon the creatures, she blasts Nina Simone on the streets — a defiant and tragic choice. The scene is framed as empowering, but it rests on the same tired idea: that life with disability, accommodations, or dependence on medication is somehow unbearable. Instead of allowing the character to fight for survival or redefine her place in this brutal world, the story sends her to a noble death.

And it's not just her. Earlier, as people walk together towards safety — in a moment when silence is crucial — the sound of the wheels of a wheelchair breaks the silence and endangers everyone: the message is clear — in the world of the film, keeping those with

disabilities in our community is a risk we simply cannot afford. In a final boat sequence, a modern Ellis Island metaphor, humanity is divided into the worthy and the expendable — those who the narrative presents as mattering make the boat, leaving the disabled and "weak" behind. It's a deeply unsettling undercurrent, suggesting that the future belongs only to those who meet a certain standard of strength and independence. This ignores the fact that historically having disabled people in communities (and efforts to accommodate them) makes everyone's life better. (In real life, if you like SMS, velcro, smart home technology, curb cuts on sidewalks, subtitles on films, and the telephone itself, you can thank the presence of disability!)

To its credit, the film is a super-engaging ride. The pacing is relentless, the tension gripping, and the performances top-notch. But at its core, it fails to embrace the complexity of its premise. Instead of exploring how communities survive together — drawing on diverse skills and perspectives — it imagines a future purified of those who don't 'fit.'

This isn't just a missed opportunity; it's a troubling choice. It's not that disabled people "want to die," as the film implies — it's that society often denies them the resources and support to fully live. *Day One* reinforces this upside-down narrative, assuring audiences that disabled folks are happy to disappear, sparing the rest of society from guilt or responsibility.

By the end of the film, the heroine's cat finds a new home with the white male lead Joseph Quinn. Nyong'o's character's legacy is reduced to a mustard sweater and a cute letter. It's a stark reminder that while the film asks us to root for survival, it really only imagines

survival for some. Humans with vulnerabilities are left behind — not because they can't

make it, but because the story never gives them a chance.

A Quiet Place: Day One (2025)

Director: Michael Sarnoski

Writers: John Krasinski, Michael Sarnoski

Cast: Lupita Nyong'o, Joseph Quinn, Djimon Hounsou, Alex Wolff, Lauren Ridloff

Genre: Horror, Sci-Fi, Thriller

Runtime: 1 hour 43 minutes

Rating: PG-13 (violence, terror, thematic elements, brief strong language)

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Dissertation & Abstracts v20i2

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Abstract

The following provides a listing of select recent citations of dissertations and theses relevant to disability studies.

Keywords: disability, disability studies, dissertations

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