Community Inclusion for People with Intellectual and Developmental Disabilities: A Call to Action for Social Work

Jade Presnell John Keesler

Abstract: Many people with intellectual and developmental disabilities (IDD) are isolated and lack meaningful opportunities to participate and develop social networks within their communities. Sharing membership with a community that fosters connection and belonging is essential to well-being. As a human rights profession, social work is uniquely situated to overcome the macro barriers that prevent full community inclusion for people with IDD. However, the experiences and needs of those with IDD have largely been left out of the profession's discourse on diversity and oppression. This article presents a call-to-action for social work to engage in strategies and solutions to resolve macro barriers to community inclusion, to dismantle the injustices that people with IDD continue to experience, and to move the promise of community inclusion from rhetoric to reality. Social workers can promote community inclusion for people with IDD through a variety of approaches, including using a human rights-based framework, aligning with personcentered planning, fostering evidence-based practices, using participatory action research, increasing disability content in social work curricula, and engaging in community action and advocacy.

Keywords: Intellectual and developmental disability; community inclusion; human rights; social work practice; social work education; macro social work practice

Community inclusion is a universal human right (Convention on the Rights of Persons with Disabilities [CRPD], 2006); however, for people with intellectual and developmental disabilities (IDD), this right is often violated. Since 1967, when deinstitutionalization began in the United States, extensive progress has been made for people with IDD, including a shift to individuals living in their communities, a surge in the delivery of individualized services, and the development of federal policies like the Americans with Disabilities Act (ADA) that prohibit discrimination against individuals with disabilities in all areas of public life (Scott et al., 2008). Yet, although these advances have fostered equality and improved the quality of life for people with IDD, physical inclusion in the community has been insufficient for their full, active, and meaningful participation in the community (Macdonald et al., 2018; Scior et al., 2020).

The social work profession is uniquely situated to address this disparity through its strengths-based approach and the advancement of core values shared among the profession and people with IDD, including social justice, dignity and worth of the person, and the importance of human relationships (John & Schrandt, 2019; National Association of Social Workers [NASW], 2020). Despite this alignment, however, people with IDD have been absent from the profession's narrative (Fuld, 2020). In 2016, the Society for Social Work and Research (SSWR) released the 12 Grand Challenges for Social Work that identified critical areas for the profession to address through a call-to-action (Williams, 2016). Two of the 12 challenges - eradicate social isolation and achieve equal opportunity and justice – are central to the quality of life for people with IDD. Thus, it is important to consider: How can social work eradicate social isolation and strive to achieve equity for people with IDD through community inclusion?

This article presents a call-to-action for the social work profession to respond to these grand challenges. We identify and discuss a series of strategies for the profession to embrace as ways to overcome the historic and contemporary barriers to community inclusion that people with IDD have encountered. Before proceeding, however, the breadth of disabilities and inconsistencies in defining inclusion necessitate explicit definitions to ensure a common understanding across readership.

Definitions

Intellectual and Developmental Disabilities. According to the American Association on Intellectual and Developmental Disabilities (AAIDD; 2021) intellectual disability is a lifelong condition characterized by limitations in both intellectual functioning and adaptive behavior that originates prior to age 22. More broadly, developmental disability is a term that includes intellectual disability, but is also inclusive of other cognitive and/or physical disabilities that present during development and are usually lifelong, such as Down syndrome, autism, and cerebral palsy (Arc of Indiana, 2021). Collectively, the trajectory of these disabilities, despite their pervasive nature, can be greatly enhanced with individualized supports and services, such that people with IDD can live independent, productive, and meaningful lives (AAIDD, 2021).

Community Inclusion. Community inclusion is defined as having full and equitable access to activities, social roles, relationships, and community belonging and membership (Cobigo et al., 2012). Inclusive communities fully embrace people with IDD and their families, ensure equal opportunity for full participation in community life, and promote a sense of full belonging. This shared membership fosters connection and promotes physical and mental wellness, as well as optimal quality of life (Dahan-Oliel et al., 2012).

Social Exclusion as a Reality for People With IDD

Community inclusion is a right for all people, however, for people with IDD this right often goes unfulfilled. Social movements, like the Disability Rights Movement, and federal legislation, such as the ADA, have fostered significant advances for persons with disabilities. Collectively, they have fostered the recognition of the importance of community inclusion; increased physically accessible environments; and improved access to education, employment, and other community-based services that promote inclusion and well-being (McCarthy, 2003). Yet, despite the individualization of supports and services and their integration of multiple life domains (e.g., education and employment; Stancliffe et al., 2000), people with IDD continue to experience discrimination, marginalization, and rights violations as evidenced by community segregation, poverty, healthcare disparities, and exclusion in education and the workforce (Amado et al., 2013; Glen, 2015; Metzel &

Walker, 2001; Mitra et al., 2013; United Nations, 2007). Even after the passing of more than 50 years since the commencement of deinstitutionalization, many people with IDD do not experience meaningful participation in their community and continue to lack supportive social networks and endure the ill-effects of exclusion (Macdonald et al., 2018; World Health Organization, 2011). Although most people with IDD now live in the community, it is evident that physical inclusion has not translated to true, meaningful community inclusion (Scior et al., 2020).

A Call to Action for Social Work

Social work has served an integral role in advancing the quality of life for people with IDD. From the early days of poor houses to contemporary practices of early intervention and parent training, advocacy and case management, and assessment and counseling, people with IDD have benefited from many supports and services provided by the social work profession (John & Schrandt, 2019; Mackelprang, 2013). However, even with such supports and services, people with IDD continue to be marginalized and excluded from full community inclusion (Macdonald et al., 2018; Scior et al., 2020). The fulfillment of their right to community inclusion is challenged by barriers of prejudice rooted in ableism and paternalism, systemic adherence to the medical model of disability, a lack of clarity in defining community inclusion, limited evidence-based practices to promote community inclusion, and a disconnect between disability-related policy and practice. Each of these barriers is briefly reviewed in Table 1.

Although the social work profession is integral in fighting inequality and injustices experienced by diverse populations, leading social work organizations like the Council on Social Work Education (CSWE) and NASW give little acknowledgement to disabilities as social issues or as contributing to human diversity (Kattari et al., 2017; Mackelprang, 2010). Likewise, social work curricula frequently lack disability content or opportunities for specialization in disabilities (John & Schrandt, 2019; Kim & Sellmaier, 2020). Although the profession has made some advances (e.g., Curricular Resource on Issues of Disability and Disability-Competent Care; CSWE, Disability-Competent Care Curriculum Workgroup, 2018), additional efforts are warranted to bolster social work with the disability community (John & Schrandt, 2019).

Through various domains and strategies, social workers can create significant momentum in furthering the quality of life and inclusion for people with IDD. These domains include using a human rights-based approach, aligning with person-centered planning, fostering evidence-based practices, using participatory action research (PAR), increasing disability content in social work curricula, and furthering community action and advocacy. Each of these domains with corresponding examples of practical strategies that social workers can use are described in Table 2.

Table 1. Barriers to Community Inclusion for People With IDD

Barriers	Considerations
Ableism	Ableism is defined as the "beliefs or practices that devalue & discriminate against people with physical, intellectual, or psychiatric disabilities &
	often rests on the assumption that disabled people need to be 'fixed'" (Smith, n.d., para. 1).
	• Ableism is embedded in many cultural beliefs, societal structures, & institutions, & has resulted in the othering & exclusion of people with IDD
	across multiple domains (e.g., healthcare, employment, & education; Friedman, 2019).
Paternalism	• Dignity of risk & the right to self-determination are often overshadowed by historical protectionist systems or superseded by caregivers' duty to
	care (Glen, 2015).
	• Paternalism has resulted in the exclusion of people with IDD from life decisions, directing their services, & from acting on their own behalf (Glen,
M. E 1	2015); "everything for the people, but without the people" (Román, 2010, p. 127).
Medical model of	• Disability is equated with physical and/or mental impairments that result in functional limitations that inhibit the ability of people with IDD to function effectively in society (e.g., work, live independently, etc.).
disability	• The government's role is to assist people with IDD through financial support & rehabilitative services to overcome these limitations (Scotch, 2000).
	• This model takes a needs-based approach, is diagnosis driven, & focuses on treating disability rather than removing structural barriers (Degener,
	2016).
	• The full realization of the social model of disability, which recognizes society as the primary cause of disablement continues to be compromised by
	the medical model that has endured over time (Scior et al., 2020).
Lack of clarity	Scholars & practitioners have failed to distinguish community inclusion from community integration, participation, & belonging (Amado et al.,
in defining	2013).
community inclusion	• The absence of a clear definition has resulted in limitations with assessing the extent to which providers achieve inclusion for the persons they
	support (Cobigo & Stuart, 2010).
Lack of evidence-	• EBP involve "a process in which the practitioner combines well-researched interventions with clinical experience, ethics, client preferences, & culture to guide & inform the delivery of treatments & services" (NASW, 2020, para 5).
based	• Interventions & practices have often originated in the general population & have lacked sensitivity to disability identity and culture. As such, they
practices	frequently require adaptations to be effective (Andrews et al., 2019; Keesler, 2020).
(EBP)	• The efficacy of disability services in facilitating community inclusion is unclear due an absence of evaluation & research. EBP for community
()	inclusion are needed to counter the effects of exclusion & its infringement on human rights (Bogenschutz & Amado, 2016; Schalock et al., 2017).
Disconnect	Community inclusion is often a primary goal for community-based services for people with IDD; however, many services are provided in
between	segregated spaces (e.g., day programs) for people with disabilities (Merrells et al., 2019).
policy &	• Services tend to focus on community presence & often result in little interaction with the broader community (Clement & Bigby, 2008).
practice	• Community inclusion for people with IDD is often predicated upon support from family or paid caregivers. As such, numerous challenges can arise
	such as aging parents, & turnover & vacancies among paid caregivers (Larson et al., 2016).
	• There is a systemic lack of understanding regarding disability & disability issues among community members & policy makers (Amado et al.,
	2011).

Table 2. Practical Strategies to Advance Community Inclusion for People With IDD

Table 2. Practical Strategies to Advance Community Inclusion for People With IDD		
Call to Action		
Domains	Practical Strategies	
Apply a Human Rights- Based Approach	 Dismantle segregation by actively engaging in evaluation of policies, practices, & programs that keep people with IDD from being fully included in their communities & advocate for inclusive practices (e.g., advocate to end programs that segregate people with IDD). Critically examine disability agency policies & practices to ensure they are in alignment with human rights standards (e.g., CRPD; United Nations, 2007). Provide rights-based training to people with IDD to promote knowledge of rights & to foster self-advocacy in exercising rights & seeking retribution when their rights are violated (Lord et al., 2007). 	
Intentionally Align with Person-Center Planning (PCP)	 Practicing PCP means respecting & upholding individual preferences & choices, even when these may conflict with agency policy & practice. This is critical as people with IDD are often denied choice in where they live, who they live with, & how they participate in their communities (Inclusion International, 2012; Tondora et al., 2020). Elevate the voices of people with IDD & respect them as the expert on their life (e.g., "do with, not for"). PCP opposes approaches that exclude people with IDD from making life decisions & self-directing their services (Tondora et al., 2020). 	
	• Engage in supported decision-making when guardianship laws & practices conflict with PCP. Supported decision-making is a tool that helps people with IDD maintain their ability to make decisions on their own behalf & communicate these to their supports (Shogren et al., 2017).	
Foster Evidence- Based Practices	 Advance EBP in the disability sector through the development of university-community partnerships that aim to foster stronger, more inclusive communities by bringing together the expertise & resources of multiple stakeholders (Jones et al., 2016). Engage in person-centered outcome evaluation to ensure alignment among current values, understanding, & best practices (Schalock & Luckasson, 2021). Participate in professional development/trainings focused on neurodiversity to ensure the provision of support is culturally relevant & anti-ableist. 	
Conduct Participatory Action Research	 Engage & partner with people with IDD to develop inclusive research practices. As such, research materials must be accessible to people with IDD (e.g., developing plain language research materials, designing inclusive recruitment strategies, using technology to decrease participation barriers, etc.; McDonald et al., 2016). Recognize that people with IDD may be reluctant to participate in research due to past harm/abuse, power differentials, & lack of existing relationships with researchers (Banas et al., 2019). Understand that people with IDD desire to be involved in & can benefit from participating in research. Various strategies have been identified to foster their inclusion & participation, including obtaining informed consent (Taua et al., 2014), as well as preparing individuals for participation, simplifying information, & improvising interview procedures (Jen-Yi et al., 2015). 	
Include Disability in Social Work Education	 Include neurodiversity in classroom discussions & content on diversity, ethics, & oppression, as well as information on the disability rights movement within content on social movements & systemic oppression (CSWE, Disability-Competent Care Curriculum Workgroup, 2018). Integrate disability studies into generalized & specialized course curricula to offer new opportunities for social work pedagogy to conceptualize disability in the context of a human rights framework (vs medical/rehabilitative models) & to better prepare social work students to competently support people with IDD (Goodley, 2010; Fuld, 2020). Offer increased opportunities for students to become involved in the disability sector through internships and/or field placements (Dinecola & Lemieux, 2015). 	
Increase Community Action & Advocacy	 Engage in individual, familial, & societal level strategies to challenge disability stigma. These can include empowering individuals with self-advocacy groups & education on legal & financial rights; parental education about IDD & peer support for family members; educating society through anti-stigma campaigns & collaboration with community leaders to foster acceptance of people with IDD in their community (Jansen-van Vuuren & Aldersey, 2020). Work with local governments & businesses to ensure that all community spaces are accessible to people with IDD. Advocate for laws & international standards that safeguard & protect people with IDD from victimization and exploitation (Scior et al., 2020). 	

Applying a Human Rights-Based Approach. Despite the often-perceived progressive nature of social work, the profession has frequently maintained a focus on the medical model and a needs-based approach (Mapp et al., 2019; Ogden et al., 2017). The medical model pathologizes disability as deviation from the norm, is diagnosis-driven, and focuses primarily on treating or rehabilitating disability. While the medical model remains deeply engrained in practices for people with IDD, there has been some movement, albeit slow, to integrate the social model of disability (Oliver, 1996) into social work education and practice (Morgan, 2012). The social model considers disability as a social construct created through discrimination and oppression. Understanding disability as a social construct shifts the focus from treating the individual to addressing societal barriers that keep people with IDD marginalized. The social model of disability also acknowledges the importance of civil rights; however, it is not fundamentally a rights-based approach to disability.

Notably, the development of the United Nations CRPD in 2006 brought with it a shift to a human rights model of disability. In contrast to the social model, the human rights model encompasses all human rights: civil, political, economic, social, and cultural rights, and does not view disability as a hinderance to human rights. Rather, the human rights perspective considers neurodiversity as a valued extension of the human experience (Degener, 2016). As such, persons with IDD are equal to others and are therefore entitled to community inclusion. Any social or environmental barriers that prevent people with IDD from realizing their right to inclusion are considered to be discriminatory and must be dismantled. Within this approach, people with IDD are recognized as experts and partners in their own care, rather than passive recipients of charity and services- as is the case in needs-driven services (Mapp et al., 2019). Notably, the social model of disability has been criticized for denying the individual experiences of disabilities (e.g., pain, compromised quality of life, etc.). However, the human rights perspective acknowledges personal challenges associated with disabilities and requires that they be considered in the context of social justice (Morris, 2001).

Further, this perspective extends beyond the social model's focus on social power and recognizes the importance of cultural and minority identification (e.g., gay pride, deaf community, etc.), such that disability identity and culture is not only acknowledged but celebrated. Similarly, a human rights model acknowledges that people with IDD are a heterogenous group who often have multiple, intersecting identities (e.g., relative to race, gender, age, etc.) that impact their social status and experience of oppression and discrimination. As such, people with IDD not only experience ableism, but also racism, genderism/sexism, ageism, and other forms of oppression that interfere with their right to community inclusion (Degener, 2016).

While social work has been identified as a human rights profession, it has not yet fully realized this assertion (Mapp et al., 2019). As such, social work can promote community inclusion by more fully embracing a human rights-based approach to critically examine and enhance disability supports and services. Echoing the International Federation of Social Workers, in 2015 CSWE charged the profession with advancing human rights, as well as social, economic, and environmental justice. Within the human rights framework,

needs are reframed as rights. As such, social workers are charged with helping individuals to have ongoing access to their rights, rather than simply responding to or fulfilling an immediate need (McPherson, 2018). By understanding the barriers and challenges to realizing one's rights through a rights-based lens, social workers are directed toward setting goals that focus on justice and equity and "long-term commitment to social and political change" (McPherson, 2020, p. 61). Hence, social workers advocating for community inclusion not only assist persons with IDD in exercising their rights but must also challenge larger systemic factors that infringe upon these rights (McPherson & Abell, 2020).

Intentionally Aligning with Person-Centered Planning. Undergirded by the person-in-environment framework and self-determination, the social work profession focuses on person-centered planning (PCP) as the hallmark of quality care for diverse groups (Washburn & Grossman, 2017). Like social work, the IDD field emphasizes PCP as its guiding philosophy "to reduce social isolation, promote friendships, and increase autonomy, competence, social contribution, and respect" (Holburn et al., 2004, p. 64). PCP emphasizes and supports an individual's vision for a preferred life through meaningful roles and active participation. Through PCP, the individual is respected as the primary decision-maker and their choice and autonomy act as guiding forces in shaping how services and supports are delivered (American Geriatrics Society Expert Panel on Person-Centered Care, 2016). This is an important shift away from hierarchical models of care that see the provider as the expert and primary decision-maker. This shift is integral to supporting the empowerment and self-determination of persons with IDD and ensuring that systems of care do not further oppress and marginalize them.

The common emphasis on PCP between social work and the IDD field has the potential to create new opportunities for increased community inclusion for people with IDD, particularly as PCP has been associated with improved social networks, increased contact with family and friends, and greater involvement in group activities (Claes et al., 2010). At times, however, social work has fallen short with critical elements of PCP (e.g., respect for the personhood of the person being supported; Washburn & Grossman, 2017). Scholars have noted that PCP requires an intentional emphasis on supporting individuals' unique goals for social relationships and community participation (Bogenschutz & Amado, 2016). Consequently, social workers need to purposefully align their practices with PCP to better support inclusion across settings.

Fostering Evidence-Based Practices. Although society has often proclaimed community inclusion for people with IDD, research has suggested a disconnect between intentions and outcomes for inclusion (Scior et al., 2020). Bogenschutz et al. (2015) identified national research goals to advance social inclusion for people with IDD. These goals included understanding contextual factors that influence social inclusion, building capacity for social inclusion, and identifying best practices for social inclusion (Bogenschutz et al., 2015). Notably, both social work and the field of IDD have called for greater emphasis on best practices and EBP (Schalock et al., 2017; Thyer & Myers, 2011). For people with IDD, interventions and practices have often originated in the general population, and as such, they have lacked sensitivity to disability culture and therefore warrant adaptations to be effective (Andrews et al., 2019; Keesler, 2020). Schalock et al. (2017) identified the importance of EBP in IDD services and emphasized a multi-systems

framework with implications of various factors (e.g., support staff strategies and opportunities for participation) for individual outcomes. Further, they stressed the need for cultural sensitivity, use of the social-ecological model, team collaboration and consultation, and the ability to work with limited resources. Given these collective considerations, social work is well-situated to embark on the development, evaluation, and advancement of EBP for inclusion.

Using Participatory Action Research. Participatory action research (PAR) can be integral to developing EBP for community inclusion of people with IDD (Powers, 2017). Well within the expertise of social work, PAR is an approach to scientific inquiry that actively engages members of an oppressed group in identifying critical issues and collaborates with them in creating solutions (Tanabe et al., 2018). Social workers can and must learn from the knowledge of persons with IDD to have a more complete understanding of what barriers to inclusion exist and how to overcome them. While engaging persons with IDD as key stakeholders is critical, they have largely been excluded from participating in the very research, policy development, and decision-making that intimately affects their lives (Dinora et al., 2020). According to Inclusion International (2012),

What is missing is the voice of people with intellectual disabilities and their families who have lived the experience of exclusion and isolation, who understand the causes and impact of that exclusion and who have a vision for what living and being included in the community should look like. (p. 9)

The voices of people with IDD must drive the inclusion movement forward. "Nothing about us without us" has been adopted by disability rights advocates to assert the importance of ensuring that persons with IDD are at the forefront of decisions that affect their lives (Charlton, 1998). Persons without disabilities do not have the experience of living with a disability and therefore do not share the same level of knowledge and insight about the issues affecting persons with IDD (Tanabe et al., 2018). Consequently, the experiences of people with IDD must be valued and they must be leading discussions, decisions, and agendas surrounding services, accessibility, and rights-based issues (Rios et al., 2016).

Over the past two decades, PAR has gained some interest from IDD practitioners and researchers given its collaborative and inclusive nature; however, despite its promise, the approach remains under-utilized (Rosner, 2015). Criticisms of traditional research focused on disability suggest that it is not representative of people with IDD, as it has largely been conducted by those without lived experience of disability, which may inaccurately reflect the experiences of people with IDD and result in further disempowerment and alienation (Rios et al., 2016). In contrast, PAR is empowering, inclusive, collaborative, authentic, and conducive to facilitating positive social change, especially for marginalized groups (Baum et al., 2006). Through this approach, persons with IDD are valued as experts on inclusion by virtue of their lived experience and respected as key contributors and partners in the research process. By focusing on PAR and elevating the perspectives of people with IDD, social work could foster a more accurate representation of the experiences of persons with IDD and more effectively build inclusive communities.

Including Disability in Social Work Education. Education is a powerful tool in the movement toward community inclusion for people with IDD. Although the disability rights movement aligns with the profession's emphasis on social justice and equity, social work education has fallen short in disability content to adequately prepare students for practice with people with IDD (Bean & Hedgpeth, 2014). This is concerning from a few perspectives: (a) people with IDD constitute a diverse population with intersecting identities and experiences; and (b) social work students become the next generation of social work practitioners, researchers, and advocates. Despite developments in national and international policies related to IDD, social workers have been rarely identified in the context of the IDD field and have largely remained invisible (Bigby & Adkinson, 2010). Unfortunately, few social work students express a desire to work with people with IDD as their targeted client population (John & Schrandt, 2019). In addition, differences among social work students in their attitudes toward people with different types of disabilities suggest a possible disability hierarchy (e.g., preference toward people with physical disabilities over people with IDD), which is counter to equity and social justice in the field (Keesler, 2019).

The experiences of people with IDD are underrepresented in social work curricula, such that neurodiversity and disability are often not considered in the context of diversity. Like people with IDD, people of color and people who are transgender have been marginalized. Although extensive efforts have focused on upholding the dignity and worth of people of color and transgender people, people with IDD continue to be largely excluded from discussion and activism on diversity and systemic oppression (Mackelprang, 2010). Further, when content does specifically address practice competencies with people with IDD, these tend to be based on medical and rehabilitative models of understanding disability that fail to consider societal and environmental factors that create challenges for people with IDD (Meekosha & Dowse, 2007).

It is plausible that increased exposure to disability content in social work programs could ameliorate these concerns. Kim and Sellmaier (2020) suggested that social work programs assess the visibility of disability in their institutional practices, explicit curriculum (e.g., course content and assignments), and implicit curricula (e.g., policies and discourse). By increasing awareness of disability in social work education through expanded disability content, the profession could foster increased interest among burgeoning social workers to enter the disability field and better prepare those who have already decided to do so (John & Schrandt, 2019; Kim & Sellmaier, 2020). Notably, in collaboration with the CSWE, the Disability-Competent Care Curriculum Workgroup (2018) developed a curricular resource guide to support the integration of disability content in social work curricula. This guide provides support for educators in identifying and linking CSWE competencies with disability learning outcomes and educational resources.

Increased Community Action and Advocacy. Although the social work profession has become increasingly focused upon clinical practices, its historic roots are in advocacy and societal change (Mapp et al., 2019). The profession's code of ethics calls social workers to action, "to prevent and eliminate" discrimination based on disability and to "promote conditions that encourage respect for cultural and social diversity...(and) promote policies and practices that demonstrate respect for difference" (NASW, 2021,

Standard 6.04). Hence, the profession is charged with meeting the needs of people with IDD and challenging macro barriers, like ableism, that prevent full community inclusion. Mackelprang (2010) noted that, "although NASW actively condemns racism, it is relatively quiet about ableism that places disabled people at risk" (p. 93). It is time for social work to partner with people with IDD to actively challenge ableist practices and structures.

Scior et al. (2020) noted that social workers could actualize these responsibilities toward people with IDD by developing resources and educating the public about IDD, by addressing and seeking an end to disability stigma and discrimination, and by advocating for laws and international standards that safeguard and protect people from victimization and exclusion because of their disability. Notably, however, social workers are also called to act within the scope of their training and expertise. Further, advocacy is often influenced by interests and passion. Collectively, expertise, interests, and passion, are often influenced by education. And, as previously noted, disability content is often limited within social work curricula. So, while social workers can and should engage in increased action and advocacy for people with IDD, their abilities to do so may be compromised by their formative academic experiences until curricular amendments are made.

Conclusion

Persons with IDD have the right to be fully included and treated as equitable members of their communities. Their quality of life is contingent upon the quality of their supports, services, and interpersonal relationships; participation in educational and recreational activities; their ability to exercise choice and independence; having access to individualized supports (versus a "one-size fits all" approach); and, living and socializing within their communities (Schalock et al., 2018). Equitable communities are realized only when all their members are recognized, valued, and included. For people with IDD, this requires the removal of all barriers that prevent them from fully exercising their right to community inclusion.

If social work espouses to be a human rights profession, then social workers must step forward and dismantle the injustices that people with IDD continue to experience. As social workers, we can no longer ignore the importance of inclusion and its positive impact on well-being. We must listen to the perspectives of those with lived experience. We must engage in creating, evaluating, and fostering effective strategies to increase community inclusion for people with IDD. We must partner with people with IDD and work alongside them, for disability rights are human rights. Because simply being *in* a community is not enough.

References

American Geriatrics Society Expert Panel on Person-Centered Care. (2016). Person-centered care: A definition and essential elements. *Journal of the American Geriatrics Society*, 64(1), 15-18. https://doi.org/10.1111/jgs.13866

Amado, A. N., DeGrande, M., Boice, C., & Hutcheson, S. (2011). *Impact of two national congregational programs on the social inclusion of individuals with intellectual/developmental disabilities*. Minneapolis, MN: University of Minnesota,

- Institute on Community Integration. https://ici.umn.edu/products/432
- Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. *Intellectual and Developmental Disabilities*, *51*(5), 360-375. https://doi.org/10.1352/1934-9556-51.5.360
- American Association on Intellectual and Developmental Disabilities. (2021). *Definition of intellectual disability*. https://www.aaidd.org/intellectual-disability/definition
- Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., Pilarski, C. R., & Balter, R. (2019). #SaytheWord: A disability culture commentary on the erasure of "disability". *Rehabilitation Psychology*, *64*(2), 111-118. https://doi.org/10.1037/rep0000258
- Arc of Indiana, The. (2021). What is developmental disability? https://www.arcind.org/families/developmental-disabilities-definition/
- Banas, J. R., Magasi, S., The, K., & Victorson, D. E. (2019). Recruiting and retaining people with disabilities for qualitative health research: Challenges and solutions. *Qualitative Health Research*, *29*(7), 1056-1064. https://doi.org/10.1177/1049732319833361
- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, 60(10), 854-857. https://doi.org/10.1136/jech.2004.028662
- Bean, K. F., & Hedgpeth, J. (2014). The effect of social work education and self-esteem on students' social discrimination of people with disabilities. *Social Work Education*, 33(1), 49-60. https://doi.org/10.1080/02615479.2012.740454
- Bigby, C., & Adkinson, D. (2010). Written out of history: Invisible women in intellectual disability social work. *Australian Social Work*, 63(1), 4-17. http://dx.doi.org/doi:10.1080/03124070903482949
- Bogenschutz, M., & Amado, A. (2016). Social inclusion for people with IDD: What we know and where we go from here. In *Critical issues in intellectual and developmental disabilities: Contemporary, research, practice, and policy* (pp. 19-36). American Association on Intellectual and Developmental Disabilities.
- Bogenschutz, M., Amado, A., Smith, C., Carter, E., Copeland, M., Dattilo, J., Gaventa, B., Hall, S., McManus, M., Quraishi, S., Romer, L., & Walker, P. (2015). National research goals for social inclusion of people with IDD. *Inclusion*, *3*(4), 211-218. https://doi.org/10.1352/2326-6988-3.4.211
- Charlton, J. I. (1998). Nothing about us without us. University of California Press.
- Claes, C., Van Hove, G., Vandevelde, S., can Loon, J., & Schalock, R. L. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities*, 48(6), 432-453. https://doi.org/10.1352/1934-9556-48.6.432

- Clement, T., & Bigby, C. (2008). Breaking out of a distinct social space: Reflections on supporting community participation for people with severe and profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 22, 264-275. https://doi.org/10.1111/j.1468-3148.2008.00458.x
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action*, *2*(2), 75-84. https://doi.org/10.5463/sra.v1i3.45
- Cobigo, V., & Stuart, H. (2010). Social inclusion and mental health. *Current Opinion in Psychiatry*, 23, 453-457. https://doi.org/10.5463/SRA.v1i1.10
- Convention on the Rights of Persons with Disabilities. (2006). https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
- Council on Social Work Education [CSWE], Disability-Competent Care Curriculum Workgroup. (2018). Curricular resource on issues of disability and disability-competent care: Diversity and justice supplement. https://cswe.org/Centers-Lnitiatives/Centers/Center-for-Diversity/Curricular-Resource-on-Issues-of-Disability-and-Di.aspx
- Dahan-Oliel, N., Shikako-Thomas, K., & Majnemer, A. (2012). Quality of life and leisure participation in children with neurodevelopmental disabilities: A thematic analysis of the literature. *Quality of Life Research*, *21*(3), 427-439. https://doi.org/10.1007/s11136-011-0063-9
- Degener, T. (2016). Disability in a human rights context. *Laws*, *5*(35), 1-24. https://doi.org/10.3390/laws5030035
- Dinecola, C. M., & Lemieux, C. M. (2015). Practice with persons with autism spectrum disorders: Predictors of self-efficacy among social work students. *Journal of Social Work in Disability & Rehabilitation*, 14(1), 23-40. https://doi.org/10.1080/1536710X.2015.989559
- Dinora, P., Schoeneman, A., Dellinger-Wray, M., Cramer, E. P., Brandt, J., & D'Aguilar, A. (2020). Using video vignettes in research and program evaluation for people with intellectual and developmental disabilities: A case study of the Leadership for Empowerment and Abuse Prevention (LEAP) project. *Evaluation & Program Planning*, 79, 1-6. https://doi.org/10.1016/j.evalprogplan.2019.101774
- Friedman, C. (2019). The relationship between disability prejudice and institutionalization of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *57*(4), 263-273. https://doi.org/10.1352/1934-9556-57.4.263
- Fuld, S. (2020). Demarginalizing intellectual and developmental disabilities in graduate social work education. *Journal of Social Work Education*, *56*(3), 508-518. https://doi.org/10.1080/10437797.2019.1656584
- Glen, K. B. (2015). Supported decision-making and the human right to legal capacity.

- Inclusion, 3(1), 2-16. https://doi.org/10.1352/2326-6988-3.1.2
- Goodley, D. (2010) Disability studies: An interdisciplinary introduction. Sage.
- Holburn, S., Jacobson, J. W., Schwartz, A. A., Flory, M. J., & Vietze, P. M. (2004). The Willowbrook Futures Project: A longitudinal analysis of person-centered planning. *American Journal on Mental Retardation*, 109(1), 63-76. <a href="https://doi.org/10.1352/0895-8017(2004)109<63:TWFPAL>2.0.CO;2">https://doi.org/10.1352/0895-8017(2004)109<63:TWFPAL>2.0.CO;2
- Inclusion International. (2012). *Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and Be Included in the Community*. https://inclusion-international.org/wp-content/uploads/2010/05/Global-Report-Living-Colour-dr2-2.pdf
- Jansen-van Vuuren, J., & Aldersey, H. M. (2020). Stigma, acceptance and belonging for people with IDD across cultures. *Current Developmental Disorders Reports*, 7, 163-172. https://doi.org/10.1007/s40474-020-00206-w
- Jen-Yi, L., Krishnasamy, M., & Der-Thanq, C. (2015). Research with persons with intellectual disabilities: An inclusive adaptation of Tourangeau's model. *Alter*, 9(4), 304-316. https://doi.org/10.1016/j.alter.2015.07.006
- John, A., & Schrandt, K. (2019). Social work practice with individuals with intellectual disability: Social work students' perspectives. *Journal of Social Work Education*, 55(4), 724-735. https://doi.org/10.1080/10437797.2019.1611511
- Jones, J. L., Gallus, K. L., & Cothern, A. S. (2016). Breaking down barriers to community inclusion through service-learning: A qualitative exploration. *Inclusion*, 4(4), 215-225. https://doi.org/10.1352/2326-6988-4.4.215
- Kattari, S. K., Lavery, A., & Hasche, L. (2017). Applying a social model of disability across the life span. *Journal of Human Behavior in the Social Environment*, *27*, 865-880. https://doi.org/10.1080/10911359.2017.1344175
- Keesler, J. M. (2019). Understanding emergent social workers' experiences and attitudes toward people with psychiatric, physical, and developmental disabilities. *Journal of Social Work Education*, *57*(1), 85-99. https://doi.org/10.1080/10437797.2019.1661916
- Keesler, J. M. (2020). Trauma-specific treatment for individuals with intellectual and developmental disabilities: A review of the literature from 2008 to 2018. *Journal of Policy and Practice in Intellectual Disabilities*, *17*(4), 332-345. https://doi.org/10.1111/jppi.12347
- Kim, J., & Sellmaier, C. (2020). Making disability visible in social work education. *Journal of Social Work Education*, 56(3), 496-507. https://doi.org/10.1080/10437797.2019.1661899
- Larson, S. A., Tolbize, M. S. A., Kim, O., & York, B. (2016). *Direct support professional turnover costs in small group homes: A case study*. University of Minnesota, Research and Training Center on Community Living.

- https://www.researchgate.net/publication/311536964_Direct_Support_Professional_ Turnover Costs in Small Group Homes A Case Study
- Lord, J. E., Guernsey, K. N., Balfe, J. M., & Karr, V. L. (2007). *Human rights, yes!* Human Rights Resource Center, University of Minnesota. http://hrlibrary.umn.edu/edumat/hreduseries/TB6/index2.html
- Macdonald, S. J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J., Ellis, G., Mathews, D., Ismail, A., Sullivan, S., Dore, S., & Highmore, L. (2018). 'The invisible enemy': Disability, loneliness and isolation. *Disability & Society*, *33*(7), 1138-1159. https://doi.org/10.1080/09687599.2018.1476224
- Mackelprang, R. W. (2010). Disability controversies: Past, present, and future. *Journal of Social Work in Disability & Rehabilitation*, 9, 87-98. https://doi.org/10.1080/1536710X.2010.493475
- Mackelprang, R. W. (2013). Disability: Overview. In *Encyclopedia of social work* (pp. 1-14). Oxford University Press. https://doi.org/10.1093/acrefore/9780199975839.013.541
- Mapp, S., McPherson, J., Androff, D., & Gatenio Gabel, S. (2019). Social work is a human rights profession. *Social Work, 64*(3), 259-269. https://doi.og/10.1093/sw/swz023
- McCarthy, H. (2003). The disability rights movement: Experiences and perspectives of selected leaders in the disability community. *Rehabilitation Counseling Bulletin, 46,* 209-223. https://doi.org/10.1177%2F003435520304600402
- McDonald, K. E., Conroy, N. E., Olick, R. S., & Project ETHICS Expert Panel. (2016). Is it worth it? Benefits in research with adults with intellectual disability. *Intellectual and Developmental Disabilities*, 54(6), 440-453. https://doi.org/10.1352/1934-9556-54.6.440
- McPherson, J. (2018). Exceptional and necessary: Practicing rights-based social work in the USA. *Journal of Human Rights and Social Work, 3,* 89-98. https://doi.org/10.1007/s41134-018-0051-x
- McPherson, J. (2020). Now is the time for a rights-based approach to social work practice. *Journal of Human Rights and Social Work, 5*(2), 61-63. https://doi.org/10.1007/s41134-020-00125-1
- McPherson, J., & Abell, N. (2020). Measuring rights-based practice: Introducing the Human Rights Methods in Social Work Scales. *British Journal of Social Work, 50*(1), 222-242. https://doi.org/10.1093/bjsw/bcz132
- Meekosha, H., & Dowse, L. (2007). Integrating critical disability studies into social work education and practice: An Australian perspective. *Practice*, *19*(3), 169-183. https://doi.org/10.1080/09503150701574267
- Merrells, J., Buchanan, A., & Waters, R. (2019). "We feel left out": Experiences of social inclusion from the perspective of young adults with intellectual disability. *Journal of*

- *Intellectual & Developmental Disability*, *44*(1), 13-22. https://doi.org/10.3109/13668250.2017.1310822
- Metzel, D., & Walker, P. (2001). The illusion of inclusion: Geographies of the lives of people with developmental disabilities in the United States. *Disability Studies Quarterly*, 21(4), 1-12. https://doi.org/10.18061/dsq.v21i4.323
- Mitra, S., Posarac, A., & Vick, B. (2013). Disability and poverty in developing countries: A multidimensional study. *World Development*, 41, 1-18. https://doi.org/10.1016/j.worlddev.2012.05.024
- Morgan, H. (2012). The social model of disability as a threshold concept: Troublesome knowledge and liminal spaces in social work education. *Social Work Education*, 31(2), 215-226. https://doi.org/10.1080/02615479.2012.644964
- Morris, J. (2001). Impairment and disability: Constructing an ethics of care that promotes human rights. *Hypatia*, 16(4), 1-16. https://doi:10.1111/j.1527-2001.2001.tb00750.x
- National Association of Social Workers [NASW]. (2020). *Evidence-based practice*. https://www.socialworkers.org/News/Research-Data/Social-Work-Policy-Research/Evidence-Based-Practice
- NASW. (2021). *Code of ethics*. https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English
- Ogden, L., Mcallister, C., & Neely-Barnes, S. (2017). Assessment of integration of disability content into social work education. *Journal of Social Work in Disability & Rehabilitation*, 16, 361-376. https://doi.org/10.1080/1536710X.2017.1392394
- Oliver, M. (1996). Understanding disability: From theory to practice. Macmillan.
- Powers, L. E. (2017). Contributing meaning to research in developmental disabilities: integrating participatory action and methodological rigor. *Research and Practice for Persons with Severe Disabilities*, 42(1), 42-52. https://doi.org/10.1177/1540796916686564
- Rios, D., Magasi, S., Novak, C., & Harniss, M. (2016). Conducting accessible research: Including people with disabilities in public health, epidemiological, and outcomes studies. *American Journal of Public Health*, *106*(12), 2137-2144. https://doi.org/10.2105/AJPH.2016.303448
- Román, B. (2010). Ethics in caregiving services for people with serious intellectual disabilities. *Journal of Applied Ethics*, 1, 121-142.
- Rosner, I. D. (2015). From exclusion to inclusion: Involving people with intellectual disabilities in research. *Tiltai*, 72(3), 119-128. http://dx.doi.org/10.15181/tbb.v72i3.1170
- Schalock, R. L., Gomez, L. E., Verdugo, M. A., & Claes, C. (2017). Evidence and evidence-based practices: Are we there yet? *Intellectual and Developmental Disabilities*, 55(2), 112-119. https://doi:10.1352/1934-9556-55.2.112

- Schalock, R. L., & Luckasson, R. (2021). Enhancing research practices in intellectual and developmental disabilities through person-centered outcome evaluation. *Research in Developmental Disabilities*, 117, 1-9. https://doi.org/10.1016/j.ridd.2021.104043
- Schalock, R. L., van Loon, J., & Mostert, R. (2018). A systematic approach to enhancing the personal well-being of children and adolescents. *International Journal of Child, Youth, and Family Studies, 9*(4), 188-205. https://doi.org/10.18357/ijcyfs94201818647
- Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2020). Intellectual disability stigma and initiatives to challenge it and promote inclusion around the globe. *Journal of Policy and Practice in Intellectual Disabilities*, 17(2), 165-175. https://doi.org/10.1111/jppi.12330
- Scotch, R. K. (2000). Models of disability and the Americans with Disabilities Act. *Berkeley Journal of Employment & Labor Law, 21*(1), 213-222. https://doi.org/10.15779/Z38V91G
- Scott, N., Lakin, K. C., & Larson, S. A. (2008). The 40th anniversary of deinstitutionalization in the United States: Decreasing state institutional populations, 1967-2007. *Intellectual and Developmental Disabilities*, 46(5), 402-405. https://doi.org/10.1352/2008.46:402-405
- Shogren, K. A., Wehmeyer, M. L., Uyanik, H., & Heidrich, M. (2017). Development of the supported decision-making inventory system. *Intellectual and Developmental Disabilities*, 55(6), 432-439. https://doi.org/10.1352/1934-9556-55.6.432
- Smith, L. (n.d.) #*Ableism*. Center for Disability Rights. http://cdrnys.org/blog/uncategorized/ableism/
- Stancliffe, R. J., Emerson, E., & Lakin, K. C. (Eds.). (2000). Community living and people with intellectual disability Part I. *Journal of Intellectual Developmental Disability*, 25(4), 263-279. https://doi.org/10.1080/13668250020019557
- Tanabe, M., Pearce, E., & Krause, S. K. (2018). "Nothing about us, without us": Conducting participatory action research among and with persons with disabilities in humanitarian settings. *Action Research*, *16*(3), 280-298. https://doi.org/10.1177/1476750316685878
- Taua, C., Neville, C., & Hepworth, J. (2014). Research participation by people with intellectual disability and mental health issues: An examination of the processes of consent. *International Journal of Mental Health Nursing*, 23(6), 513-524. https://doi.org/10.1111/inm.12079
- Thyer, B. A., & Myers, L. L. (2011). The quest for evidence-based practice: A view from the United States. *Journal of Social Work*, 11(1), 8-25. https://doi.org/10.1177/1468017310381812
- Tondora, J., Croft, B., Kardell, Y., Camacho-Gonsalves, T., & Kwak, M. (2020). Five competency domains for staff who facilitate person-centered planning. National Center on Advancing Person-Centered Practices and Systems.

- $\underline{\text{https://ncapps.acl.gov/docs/NCAPPS_StaffCompetencyDomains_201028_final.p}} \ df$
- United Nations. (2007). From exclusion to equality: Realizing the rights of persons with disabilities. Author. https://www.un.org/disabilities/documents/toolaction/ipuhb.pdf
- Washburn, A. M., & Grossman, M. (2017). Being with a person in our care: Person-centered social work practice that is authentically person-centered. *Journal of Gerontological Social Work*, 60(5), 408-423. https://doi.org/10.1080/01634372.2017.1348419
- Williams, J. H. (2016). Grand challenges for social work: Research, practice, and education. *Social Work Research*, 40(2), 67-70. https://doi.org/10.1093/swr/svw007
- World Health Organization. (2011). World report on disability. Geneva, Switzerland: Author. https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability

Author note: Address correspondence to Jade Presnell, School of Social Work, Indiana University, Indianapolis, IN, 46202. Email: <u>jadepres@iu.edu</u>