Inclusion

‘We need to be able to connect with people.’ Leveraging Direct Support Professionals’ Perspectives to Advance Social Inclusion

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Abstract:	Social inclusion is an important quality of life indicator; however, many people with intellectual and developmental disabilities (IDD) continue to be excluded. Although direct support professionals (DSPs) can be integral to fostering the inclusion of people with IDD, there is a lack of empirical inquiry regarding their perspectives and experiences in this domain. Through semi-structured interviews, this study explores the beliefs and experiences of DSPs (n = 21) surrounding social inclusion. A constructive grounded theory approach to analysis revealed four major categories - balancing role responsibilities and individual preferences, DSPs as gatekeepers to inclusion, systemic barriers to inclusion, and creating opportunities for inclusion. By better equipping DSPs with inclusion-specific resources and skills there is substantial potential to advance social inclusion.

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‘We need to be able to connect with people.’ Leveraging Direct Support Professionals’ Perspectives to Advance Social Inclusion

Social inclusion is an important quality of life indicator; however, many people with intellectual and developmental disabilities (IDD) continue to be excluded. Although direct support professionals (DSPs) can be integral to fostering the inclusion of people with IDD, there is a lack of empirical inquiry regarding their perspectives and experiences in this domain. Through semi-structured interviews, this study explores the beliefs and experiences of DSPs (n = 21) surrounding social inclusion. A constructive grounded theory approach to analysis revealed four major categories - *balancing role responsibilities and individual preferences*, *DSPs as gatekeepers to inclusion*, *systemic barriers to inclusion*, and *creating opportunities for inclusion*. By better equipping DSPs with inclusion-specific resources and skills there is substantial potential to advance social inclusion.

Key words: social inclusion, intellectual and developmental disability, direct support professionals

Introduction

Guided by the philosophy of inclusion, home and community-based services for people with intellectual and developmental disabilities (IDD) emphasize independence and skill development in the areas of daily and community living, socialization, and self-care (Neely-Barnes & Elswick, 2016). For many people with IDD, direct support professionals (DSPs) – paid caregivers employed within the disability service industry - provide much of this habilitative support, helping them to reach their fullest potential and be included in all aspects of society (Friedman, 2018). Yet, despite the value of these supports, many people with IDD experience high levels of social exclusion and are without meaningful opportunities to actively engage with their communities and develop social networks (Macdonald et al., 2018). Further efforts to understand and develop effective strategies for promoting the social inclusion of people with IDD are warranted. Through qualitative research, we explored the perspectives of DSPs regarding social inclusion of people with IDD. The interactions between DSPs and people with IDD provide a unique context for the examination of factors that facilitate and hinder social inclusion, and the subsequent development of innovative practices to promote inclusion.

Background

Social Inclusion

Social inclusion is a multidimensional construct that has evolved following the historical practices of institutionalization and the exclusion of people with IDD from mainstream society. It is defined as having full and equitable access to activities, social roles, and relationships across settings (Cobigo, 2012). Social inclusion results from a complex interplay of personal and environmental factors that increase a person’s ability to engage with and contribute to society in a personally meaningful way. As a universal human right outlined in the Convention on the

Rights of Persons with Disabilities (2006), social inclusion is an important quality of life indicator with the assumption that participation in valued roles, activities, and relationships is essential to experiencing good quality of life (Brown et al., 2015).

In 2015, Bogenschutz and colleagues identified national research goals to advance social inclusion for those with IDD, including: understanding contextual factors that influence social inclusion, building capacity for social inclusion, and identifying best practices for social inclusion. This agenda reflects the need to ensure that what is being learned through the research on social inclusion is used to inform, advance, and improve policy and practice. The benefits of social inclusion have been well-noted amid more than 20 years of research: increased social opportunities (McConkey et al., 2013), enhanced well-being (Azaiza et al., 2011), a greater sense of belonging (Mactavish et al, 2000), the acquisition of new skills (Siperstein et al., 2009), the development of citizenship responsibilities (Ware et al., 2007), and involvement in gainful employment (Taylor, 2020). Despite this evidence and our witness to advances in services for people with IDD, further work is required to advance inclusion.

Barriers and Enablers to Social Inclusion

Individuals with IDD often face significant isolation and lack of acceptance in their communities, despite receiving various levels of support (Scior et al., 2020). Their time in the community is routinely directed by support staff and limited by small social networks (Milner & Kelly, 2009), thus leading to high levels of loneliness and restricted opportunities for meaningful community participation and engagement (Macdonald et al., 2018).

Current efforts to promote social inclusion primarily focus on facilitating local activities like group outings. Although these activities may meet service-driven goals and provide community presence, they often fail to foster a sense of belonging or personal connectedness

(Clement & Bigby, 2009; Verdonschot et al., 2009). The abilities of individuals with IDD to form meaningful community relationships and achieve full social inclusion are further hindered by insufficient training in community safety, lack of access to reliable and well-trained support staff, lack of transportation and accessible community spaces, and discriminatory attitudes (Abbott & McConkey, 2006).

Progress towards social inclusion for people with IDD has been slow due to theoretical and practical obstacles. For example, conceptual ambiguity regarding ‘social inclusion’ has contributed to unclear program goals and hindered effective service provision (Simplican et al., 2015). Further, insufficient evaluative research has compromised our knowledge of the efficacy of programs designed to promote social inclusion. However, some effective strategies include active mentoring, participation in community groups, arts-based programming (Bigby et al., 2018), supported social groups (Wilson et al., 2017), integrated activities and environments for people with and without disabilities (Amado et al., 2012; Smith, 2007), supported decision making (Shogren et al., 2015), and person-centered approaches (Bigby et al., 2018).

Role of Direct Support Professionals

Social inclusion for many people with IDD is predicated upon having support from paid caregivers like DSPs (Larson et al., 2016), yet the degree to which they are successfully included in their communities is often influenced by the paid caregiver (Bigby & Wiesel, 2015; Overmars-Marx et al., 2014). Scholars have noted an association between DSP characteristics (e.g., attitudes, beliefs, and knowledge) and the opportunities for learning and social inclusion that they provide to the individuals they support (Beckwith & Matthews, 1995; Venema et al., 2015). Although positive attitudes toward social inclusion is most favorable for *actual* inclusion, DSPs may have a limited understanding of inclusion and focus more on community presence, rather than active participation in the community (Clement & Bigby, 2009). Similarly, they may find social inclusion to be unrealistic or unachievable for people those with higher support needs (Bigby et al., 2009). However, despite their side-by-side efforts with people with IDD, little is known about how DSPs might contribute to broader efforts to advance social inclusion.

Study Purpose

Full inclusion has yet to be achieved for many people with IDD (Amado, et al., 2013; Overmars-Marx et al., 2014). Amid continued disparities in inclusion and the importance of DSPs in supporting people with IDD, gaining an understanding of DSPs' perspectives regarding social inclusion may provide critical insight for creating viable strategies and solutions. This study sought to understand DSPs' experiences and perspectives regarding social inclusion for people with IDD through the following research questions: (a) How do DSPs describe their role and responsibilities in promoting social inclusion? (b) What challenges exist in promoting social inclusion? (c) How can DSPs better support social inclusion for people with IDD?

Methods

A qualitative study was conducted among DSPs supporting people with IDD in one midwestern state to answer the research questions. Twenty-one online interviews were conducted using a semi-structured guide. The data were analyzed using a grounded theory approach which allowed for analytic flexibility and a deep understanding of DSPs' experiences and perspectives.

Data Collection

Following approval by the authors' university review board, three disability service agencies were solicited and agreed to participate in this study. These agencies had long histories of serving people with IDD, a large pool of DSPs, and had missions committed to supporting social inclusion of people with IDD. The research team had prior relationships with two of the three agencies. DSPs were recruited using purposive and snowball sampling methods. Inclusion criteria required DSPs to be employed full-time with their respective agencies for at least 6 months. Prospective participants were recruited via agency email listservs. A single point of contact at each agency sent out a recruitment email with a description of the study provided by the research team. Recruitment emails were sent out weekly over a one-month period at each organization. DSPs expressed their interest in participation by contacting the primary researcher.

The interviews were conducted via Zoom and audio recorded for subsequent transcription. The primary researcher facilitated the interviews using a semi-structured interview guide that was developed for this study. The questions were informed by the peer-reviewed literature on inclusion and in consultation with an expert in disability research. The interview included eight sociodemographic questions and eight questions on social inclusion (see Table 1). Early in the interview process, respondents were asked to describe social inclusion in their own words. They were subsequently provided with a common definition of social inclusion to strengthen the validity of responses (Cobigo, 2012). On average, interviews took approximately one hour, and all respondents received a $20 gift card for their participation.

Data Analysis

All interviews were transcribed and analyzed using constructivist grounded theory (Charmaz, 2014; Glaser & Strauss, 1967). The analysis emerged from an inductive approach and an iterative process in which the primary researcher went back and forth between the data and analysis. The ongoing process of data analysis began with the first interview and continued for three months following the completion of the last interview. Memos were written following the interviews and during analysis to record the primary researcher’s thoughts and ideas. Open coding, in which conceptual labels are created to identify information as it emerges from the data, was used. A constant comparative method among the data, codes, and memos was used to ensure the findings remained grounded in the data and to identify emerging categories that would contribute to a better understanding of DSPs' perspectives on promoting inclusion for people with IDD (Saldaña, 2016). The goal of this study was not to fully develop a grounded theory, but to identify from the data the major categories in response to answering the three research questions.

Several strategies consistent with the grounded theory framework were used to increase the trustworthiness, credibility, and rigor of the analysis. These included maintaining a detailed audit trail of all research activities (Lincoln & Guba, 1985), keeping a reflexivity journal to explore and examine researcher positionality and bias throughout the research process (Charmaz, 2014; Koch, 2006), and conducting member checking (Creswell & Miller, 2000). The primary research used reflexive journaling to document their personal thoughts and biases throughout the study. This was used to help track developing thoughts, reflect on the analyses, and provide insight regarding subjectivity. To improve the reliability of the analysis, peer debriefing was employed. This process involved a secondary researcher reviewing the interpretations and findings to reduce bias and confirm the data interpretation (Ahmed, 2024). In a similar vein, member checking was implemented through 15-minute follow-up phone conversations with DSPs. During these discussions, the primary researcher went over their data interpretations with the DSPs to verify their accuracy. This also allowed the DSPs to confirm or suggest modifications to the interpretations (Ahmed, 2024).

Participants

Twenty-one DSPs employed across three disability service agencies located in one midwestern state participated in the study. Descriptive statistics for respondent demographics can be found in Table 2. Respondents primarily identified as women (95.2%) and white/Caucasian (81%). Respondent ages ranged from 22 to 68 with an average age of 50 years old (*SD* = 13.83). Two-thirds of the sample had a college degree (66.7%). Within their agencies, five respondents served multiple roles/responsibilities (e.g., DSP and trainer, team leader, etc.). The majority of respondents worked in residential settings (76.1%). On average respondents had been working with their respective agencies for nearly nine years (*M* = 8.79, *SD* = 8.62), which was similar to the average numbers of years working as a DSP (*M* = 9.76, *SD* = 7.30). The duration of their experiences as a DSP ranged from one to 30 years.

Results

Four major categories emerged from the analysis: *balancing role responsibilities and individual preferences*; *DSPs as gatekeepers to inclusion*; *systemic barriers to inclusion*; and *creating opportunities for inclusion*. These categories and their codes are shown in Figure 1. A description of each category and the corresponding codes are subsequently presented. Each code is illustrated by quotes from the DSP interviews. All codes exceeded a recommended minimum threshold of being shared by one quarter of study participants (Harding, 2013).

Balancing Role Responsibilities and Individual Preferences

This category describes DSPs' beliefs on social inclusion and how DSPs work to balance their responsibility for promoting inclusion with the individual preferences and choices of the people they support. This category includes two codes: "inclusion as normative and vital to well-being" and "respecting choice and individualizing support needs".

Inclusion as normative and vital to well-being. All (n = 21) respondents described social inclusion as important for quality of life, noting it as a "very important" contributor to well-being. They associated social inclusion with multiple benefits, including increased social circle, improved self-esteem, and resilience. One DSP shared, “I think being included gives you a much more well-rounded life. You know I think everybody, no matter what their level of understanding or verbalization or whatever, wants to be included” (Respondent 9). DSPs consistently identified supporting social inclusion as an important responsibility of their role and often equated it with providing people with IDD the full range of opportunities, experiences, and activities (e.g., shopping, eating out, employment) to live a “normal life”. Many (n = 16) indicated there weren’t any situations in which they felt like people with IDD could not be included unless environments were physically inaccessible.

> So, yeah, to be accepted for who you are. I mean, belonging is one of those essential needs that we have. And it really detracts from mental health when you don't have that kind of social connection with anybody. When you feel like you're not included. Remember Cheers, ‘where everybody knows your name’- someone wants that kind of feeling that someone knows who they are. That they have a meaningful life (Respondent 8).

Respecting choice and individualizing support needs. DSPs acknowledged that people with IDD- like others- have varying social preferences. They described the unique personalities and strengths of the people they support, as well as the wide range of individual preferences for activities (e.g., library, casino, vacations, etc.). DSPs asserted that successful inclusion, especially for aging adults, was predicated on the respect of individual choices and preferences for how and to what degree people with IDD want be included. This is exemplified by one DSP who noted, “I let the clients choose. If they don't know, then I'll offer options. But I let them choose” (Respondent 7). Many (n = 18) DSPs normalized the need for support among people with IDD. They asserted that the degree and type of support (e.g., having DSPs participate alongside them, positive praise and encouragement, transportation to and from activities) needs to be based upon individual capabilities, strengths, needs, and preferences.

> They are people just like us, they all need a little support. We all need a little support, and some people need more than others. We're all people, doesn't really matter how much support we need, we all should be included in everything… What I like about the organization I work with is that all the plans are individualized. So, it's not a cookie cutter situation. Everything's tailored to the individual (Respondent 8).

Direct Support Professionals as Gatekeepers to Inclusion

The second category describes the role of the DSP as a gatekeeper to inclusion across settings. DSPs played a pivotal role in helping those with IDD participate in their community and providing the necessary skills training to promote inclusion and acceptance of people with IDD. This category encompasses two codes: "opening doors to new experiences and opportunities" and "skills training to promote inclusion and acceptance".

Opening doors to new experiences and opportunities. DSPs most often reported promoting social inclusion by sharing ideas, encouraging participation, and aiding in accessing opportunities (e.g., transportation). A DSP stated, "Trying to find opportunities, trying to educate people. And just trying to be as successful as we can be trying to get those doors opened" (Respondent 17). Many (n = 16) identified supporting social inclusion by "generating ideas" for activities (e.g., watching fireworks or attending community events). Others encouraged participation in new activities to expand people with IDD's interests and experiences.

> …To find things that they really want to engage in… and develop their hobbies and interests and not necessarily just places I'm familiar with or want to go. I have gone to a lot of places that I never would have thought about, because if that's what that person is

> interested in- once we develop the relationship to find out what they want to do (Respondent 14).

DSPs noted a degree of “planning” to help people with IDD participate in their communities, especially when faced with barriers (e.g., lack of transportation or staffing). They took various steps to facilitate inclusion, such as requesting discounted admission tickets, arranging transportation, and educating community members to be more accepting of those with IDD. Often, DSPs identified that their presence helped people with IDD feel more comfortable navigating new experiences and overcoming “social anxiety”.

Skills training to promote inclusion. All DSPs acknowledged their responsibility to provide supports that assisted people with IDD in experiencing social inclusion, ranging from social skills training to advocacy to participating alongside them. Most DSPs (n = 19) noted that the people they supported experienced challenges with recognizing and adapting to social norms, which can interfere with building relationships, employment, and community acceptance. DSPs shared that they were expected to provide the training, coaching, and modeling (e.g., communication, problem solving, and conflict resolution) to help people with IDD successfully navigate social situations and demonstrate increased independence.

> I mean the goal is for them to be as independent as they can and for staff to assist in that. We're not there to you know to just run their life. We're just there to kind of help them be able to live as best as they can and teach them how to be as independent as they can. Not everybody that's in a group home will stay in a group home (Respondent 3).

Systemic Barriers to Inclusion

This category describes barriers that DSPs faced when promoting social inclusion and includes four codes: “disability disempowerment”, “inaccessible communities”, “exclusion by services”, and “lack of meaningful agency training and support.”

Disability disempowerment. Respondents described a range of community experiences when supporting people with IDD. Despite positive experiences, there were accounts of how others’ perspectives of disability disempowered people with IDD and created unwelcoming spaces for them. Many (n = 15) DSPs reported negative attitudes and “judgment” from community members. For example, one respondent recalled an incident in which they were harassed by a restaurant patron when an individual they were supporting needed additional dining support. Overwhelmingly, DSPs acknowledged encountering low expectations and inaccurate assumptions regarding the capabilities (e.g., underestimation of skills and overestimation of required support) and contributions of people with IDD among community members. This is exemplified in the words of one DSP: “I've noticed even like when people can't speak, people think that they're not very smart or they don't understand. I learned very quickly that that is not the case. I had a client teach me that” (Respondent 8).

Inaccessible communities. Inaccessibility was identified as an ongoing challenge that limited where people with IDD could go in the community and the activities in which they could participate. Community settings often failed to accommodate individuals’ physical, sensory, and communication needs (e.g., stores could be loud, crowded, and inaccessible to those who used adaptative equipment).

> But when I have groups and our advocacy group, we have multiple people in wheelchairs, so we always have to make sure wherever we're going or whatever, it's

> accessible- fully accessible- the bathrooms are accessible and all that sort of stuff. We're always checking (Respondent 14).

Exclusion by services. DSPs identified systemic and service-level barriers to promoting social inclusion (e.g., lack of funding to support inclusion). People with IDD were often left with limited support due to high turnover and limited staff members, and, as a result, were unable to participate in preferred activities or participated in non-preferred activities with housemates. DSPs acknowledged that waiver budgetary constraints provided individuals with limited support across settings, especially in the workplace. When discussing these barriers, one DSP stated, "She really wanted to go to church and that's like where she felt comfortable being, but they kept telling her she couldn't go because we didn't have staff to take her" (Respondent 7). Notably, people with IDD living in group homes and those with legal guardians appeared to be disproportionately impacted by systemic barriers and, according to DSPs, often experienced fewer opportunities for inclusion.

Lack of meaningful agency training and support. Although agencies were perceived as doing their best to support inclusion, DSPs overwhelmingly reported having little to no training on *how* to support social inclusion in meaningful, effective ways. Issues surrounding staff competency and safety concerns related to severity of disability or behaviors were sometimes cited as a barrier to inclusion. Some DSPs (n = 8) also noted that the staffing crisis had comprised the quality of DSP training and onboarding process.

> Well maybe work with the staff that is reluctant [to take people with IDD into the community]. Maybe work with them a little bit and give them some ideas on how to make it work… how to make it easier and more comfortable for them. If they're comfortable with it then they'll do it… talk to them more and really kind of talk about it

> more specifically, and how to make it work- maybe that would be a good thing (Respondent 9).

Further, when training on inclusion *was* provided, it often focused on health and safety (e.g., how to respond to health or behavioral crisis). Additionally, many DSPs (n = 17) reported that their agency provided few resources to support inclusion.

Creating Opportunities to Advance Inclusion

The fourth category acknowledges DSPs strengths and insight to advance inclusion for people with IDD. DSPs suggested that new opportunities for inclusion could be realized by more fully utilizing the expertise of DSPs through collaboration and moving beyond programming to embracing inclusion as a way of life. This category has two codes: “valuing DSPs’ expertise and involvement” and “from programs to a way of life”.

Valuing DSP’s expertise and involvement. Most DSPs (n = 19) discussed how valuable their role was in supporting the well-being of the people with IDD. They described having intimate knowledge on supporting people with IDD (e.g., recognizing and responding to individuals’ triggers) and the importance of their advocacy to foster social inclusion.

> …. Having a support person or DSP enables them to live a fuller life and have all of the possibilities available to them… If I can see him getting agitated- and I know his triggers- I’ll just remove him from the situation. It's like, ‘OK, let's go to the park’ or ‘let's go do something else’, or ‘we'll come back later’. Because everybody has a bad day… we'll just regroup and take a break (Respondent 16).

Despite their expertise and their responsibility in executing person-centered plans, DSPs were rarely involved in the planning process for the people they support (e.g., team members did not seek out their input or consult with them on support needs or goals). As one respondent put it, “They’re just telling us what to do.” Collectively, DSPs expressed that it would be beneficial if they had more of a “voice” in service planning and delivery. One respondent asserted, “DSPs should have more of a voice in the programming of the clients that are being served. A better team concept, and more knowledge, more opportunities, more possibilities” (Respondent 4).

From programs to a way of life. DSPs most often identified that their agency had inclusion “programming”, including self-advocacy groups, faith-based activities (e.g., Bible study), community events promoting disability awareness, and social events specifically for people with IDD (e.g., prom). Social inclusion was seen as both a service and an outcome for people with IDD.

> Also, my agency is big on advocacy for the community. And so, they're often, you know, planning big events around the community that everyone is invited to, not just clients, so that people can be educated and integrate with individuals with disabilities, and stuff like that (Respondent 6).

DSPs referred to the desire to be included as a fundamental human need that, when fulfilled, contributes to positive identity development. They asserted that people with IDD should be “given a chance” to be included and have access to accommodations, so that they can fully participate in society. Notably, many DSPs (n = 14) perceived social inclusion as a personal experience that encompassed a sense of belonging and connectedness, and a means for building social capital and self-efficacy.

> Working as a DSP, I like it when clients feel a part of where they're at…it makes my heart happy to see that they can feel included, and in people's lives that they normally wouldn't meet otherwise….When we go to the same store all the time, we get to know people. It's a part of our circle… If they have a rhythm and they get to know people…We

> want to get to all these different places and they're connecting with all these people. And that can have an impact on their lives and they're going to have an impact in their life… what we all want, even without IDD, we need that social capital. We need to be able to connect with people (Respondent 8).

Discussion

The present study explored DSPs' perspectives and experiences surrounding advancing social inclusion of people with IDD within the provision of home and community-based services. DSPs reported highly valuing inclusion across settings and associated inclusion with many benefits that contribute to people with IDD living self-directed, meaningful, and socially connected lives. However, it is important to understand the results within the context of the current sample (i.e., predominantly White women); this is discussed further in the limitations.

The experiences of DSPs in supporting the social inclusion of people with IDD is presented in Figure 1. The figure's vertical structure indicates a dynamic and additive process among categories toward advancing inclusion. Analysis of the interview data revealed a mutual relationship between persons with IDD and DSPs, combining individual preferences and support needs with DSP values, knowledge, and effort. DSPs' recognition of the contribution of social inclusion to quality of life and the importance of respecting individual preferences creates a foundation to advance social inclusion. Further, as DSPs support individuals, they generate ideas and help plan opportunities for social inclusion, thereby serving as gatekeepers to inclusion. While DSPs foster social inclusion, they often encounter and must circumvent systemic barriers such as a lack of support in their organization, and disability disempowerment in the community. Curved arrows are used in the figure to represent the "surrounding nature" of systemic barriers to social inclusion. The path to advancing social inclusion includes the recognition of DSP expertise as they support individuals daily, and a shift in perspective, recognizing social inclusion as a way of life. The emerging relationships among the figure components can be understood through a socio-ecological lens, which has been used in previous research to understand interactions between people and their environments and the implications these have for inclusion of people with IDD in the community (Amado et al., 2013; Simplican et al., 2015).

When exploring DSPs' responsibilities for advancing inclusion, DSPs consistently identified promoting social inclusion as an important job responsibility. They often carried out this responsibility by assisting people with IDD in attending community events (e.g., festivals, concerts) or visiting community spaces (e.g., library, store, museum). Consistent with findings from Clement & Bigby (2009) DSPs most often equated social inclusion with having a presence in the community. Alternatively, building relationships (e.g., by joining a faith-based community) and finding valued roles in the community (e.g., becoming a volunteer) appeared to be less valued.

This distinction is notable as Cobigo (2012) described roles and relationships as valuable aspects of social inclusion. Further, people with IDD often report lacking social networks and support and experiencing high levels of loneliness (Macdonald et al., 2018**)**. Placing more emphasis on helping people with IDD expand and strengthen their social networks by building relationships with others through community involvement appears to be particularly impactful given that many adults with IDD report having few natural supports and friendships outside of family and paid caregivers (Merrells et al., 2019). Therefore, DSPs would benefit from guidance and support by agencies in helping the people they support to develop meaningful relationships with others in their community (e.g., neighbors, business owners). This guidance should include training on effective strategies DSPs can utilize to facilitate and support positive encounters with others in the community, such as those described by Bigby and Wiesel (2015).

Additionally, DSPs asserted that with the appropriate support and accommodations people with IDD can be successfully included across settings. Consistent with previous literature DSPs identified that opportunities for inclusion can be contingent on functionality, such that those with higher support needs experience more barriers in accessing and participating in the community and work (Bigby et al., 2009). However, DSPs in this study noted that improvements could be made in this area if DSPs were provided with more in-depth training on how to support those with high behavior and support needs in the community. Those with higher support needs should not be excluded from experiencing the psychosocial benefits of inclusion (CRPD, 2006).

When exploring what challenges exist in promoting social inclusion, DSPs identified several systemic barriers, such as a lack of meaningful agency training and support surrounding inclusion. Yet DSPs often spoke favorably about the people they support, frequently noting their strengths, capabilities, and interests. While many DSPs identified themselves as being important advocates alongside the IDD community, they also reported that those they supported experienced negative encounters in the community ranging from stigma to discrimination. Specifically, they identified a lack of acceptance, negative attitudes, and low expectations toward people with IDD as significantly limiting opportunities for community engagement. Further, DSPs noted that when people with IDD are evaluated for different roles, such as an employee or volunteer, the evaluations are often based on *perceived functionality*, which may not align with actual support needs. Unfortunately, these experiences are consistent with prior research and highlight the underlying stigma and discrimination toward people with IDD as driving forces of exclusion (Scior, 2020). Moving forward, agencies should better equip DSPs in responding to ableist encounters that limit opportunities for inclusion, as well as engage in larger initiatives to promote the rights of people with IDD.

The social model of disability provides a framework for understanding systemic barriers as hinderances to inclusion. Although the model underscores the salience of inclusion, choice, and well-being for people with disabilities, it also recognizes that these can be fostered or hindered by social structures and societal attitudes (Kimberlin, 2009). Thus, the disability itself does not limit full and equal participation in society, but rather societal beliefs and stereotypes surrounding what it means to be ‘disabled’. The social model of disability emphasizes effort toward changing attitudes, cultural norms, and structures to make society more accessible and inclusive, rather than focusing on improving the functional limitations associated with disabilities (Oliver & Barnes, 2010). To advance social inclusion, it is imperative that disability organizations shift away from a needs-based approach to the social model of disability; doing so would lend to creating inclusive communities through systemic, macro-level change. Further, the social model of disability positions the disability service industry to challenge systemic barriers to inclusion; therefore, it should be expected that agencies do not further marginalize or exclude people with IDD by not providing appropriate accommodations and support, such as accessible transportation and well-trained caregivers.

DSPs appear uniquely situated to serve as an important resource and catalyst for promoting the social inclusion of people with IDD. They expressed favorable attitudes toward their work supporting people with IDD and believed their role to be influential in the lives of those they support (Lunsky et al., 2014). Many shared having intimate knowledge of people’s preferences, progress toward goals, and support needs. Despite this expertise, DSPs indicated little involvement with person-centered planning. They often felt devalued and underutilized by agency leadership. If progress is going to be made toward inclusion, DSPs must have a voice in person-centered planning and service planning and delivery (Macbeth, 2011).

Additionally, DSPs believed their agencies were supportive of inclusion based on the programming they offered. However, some DSPs indicated that inclusion could not be fully realized via a service or program, but rather requires a shift in perspective toward a way of being in the world that contributes to living a good life. Shifting from inclusion as programming to inclusion as a value is a necessary step in advancing inclusion. This will require agencies to critically evaluate how well their services, policies, and practices align with the value of inclusion. As such, agencies must first develop a shared definition of and common language surrounding inclusion to ensure consistency across stakeholders. Further, ensuring that policies and practices align with person-centered planning approaches and self-determination is critical.

Implications

Our findings have several implications for advancing the social inclusion of people with IDD. It may be important for organizations to review and enhance their efforts to equip DSPs with the resources, training, and skills to assist the IDD community in being included across settings. Based on our study, training should respond to the complexity of social inclusion, above and beyond health and safety. The DSPs in this sample acknowledged the need for strategies and resources to support people at all levels of need, to navigate barriers to inclusion, and to become more effective advocates. Further, while it is prudent to emphasize health and safety, doing so may directly conflict with promoting inclusion. Denying persons with IDD opportunities for reasonable risk-taking in their daily life hinders personal development and opportunities for growth and connection (Perske, 1967). For example, new experiences oftentimes involve some level of risk – “Dignity of risk is a part of the pathway to a full life experience” (Bumble et al., 2022, p.65).

The study’s findings recommend that organizations assess how effectively their structures, services, and resources promote inclusion. Potential strategies include: (a) evaluating the extent of collaboration among diverse roles within the organization to improve the quality of life for individuals with IDD; (b) establishing cultures of equity that leverage the expertise of DSPs to ensure individuals with IDD have equitable access to activities, roles, and relationships across various settings; (c) instructing support teams on collaborative methods to enhance inclusion and address obstacles; and, (d) encouraging collaboration with DSPs to collect data on individuals’ interests, strengths, skills, and support needs to further inclusion. Moving away from a needs-based service delivery model could shift the focus from individual impairment to systemic barriers that hinder individuals with IDD from experiencing and benefiting from inclusion. While agency-directed programs provide significant opportunities for inclusion, additional efforts to address systemic and community barriers are required to create more inclusive communities.

Limitations

Our research illuminates social inclusion from the perspective of DSPs, however, it does so with some limitations. First, qualitative research does not lend to generalizability of findings, however, our results reflect the depth and breadth of DSP experiences from multiple organizations. Second, the primary researcher conducted the interviews and completed the primary data analysis. Although there is a risk of researcher bias, the credibility and trustworthiness of analyses were fostered through various analytic strategies (e.g., note-taking, reflection, consultation with secondary researcher), examination of prior research, and researcher expertise with IDD (Shenton, 2004). Third, data were collected from only DSPs. Triangulation of the data with input from other organizational stakeholders, such as leadership and people with IDD, would further foster credibility. Fourth, DSPs frequently reported that their organization's reputation and partnership with other community entities enhanced opportunities for inclusion (e.g., churches, volunteer organizations). As such, it is unclear if DSPs employed with different agencies would have similar perspectives and experiences. Fifth, DSPs had an average of 10 years of experience working in direct support. This length of employment is atypical given the 50% turnover rate for DSP within the first year of employment (National Core Indicators, 2019). Further, recruitment of DSPs was a challenge, even with the provision of an incentive. This research was conducted during the COVID-19 pandemic which exacerbated challenges with the workforce, including turnover and increased responsibilities (Hall et al., 2022). This may explain the predominance of DSPs with longevity in this study. Finally, the diversity of our sample was limited with White women most often being represented (76.2%). This contrasts with national-level data from the 2021 *State of the Workforce Survey Report*, where 38.6% of DSPs were White and 71.2% were women (National Core Indicators Intellectual and Developmental Disabilities, 2022). Although sample differences may be influenced by local demographics (i.e., less ethnic diversity), the actual reason for these disparities is unknown. As such, some caution is warranted with the interpretation of the study findings.

Overall, DSPs valued social inclusion for people with IDD. They indicated supporting inclusion as an important job responsibility, however, doing so was often limited to facilitating community presence and participation. DSP involvement in promoting inclusion is often hindered by organizational cultures that exclude DSPs from involvement in important activities, such as person-centered planning, as well as larger systemic barriers, such as disempowering and discriminatory attitudes towards disability. Efforts must be made to enhance DSP training and support regarding social inclusion for people with IDD. Our results provide an impetus for shifting how organizations leverage the expertise of DSPs as stakeholders in the inclusion movement.

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Figure 1

Direct Support Professionals' Experiences of Supporting Social Inclusion

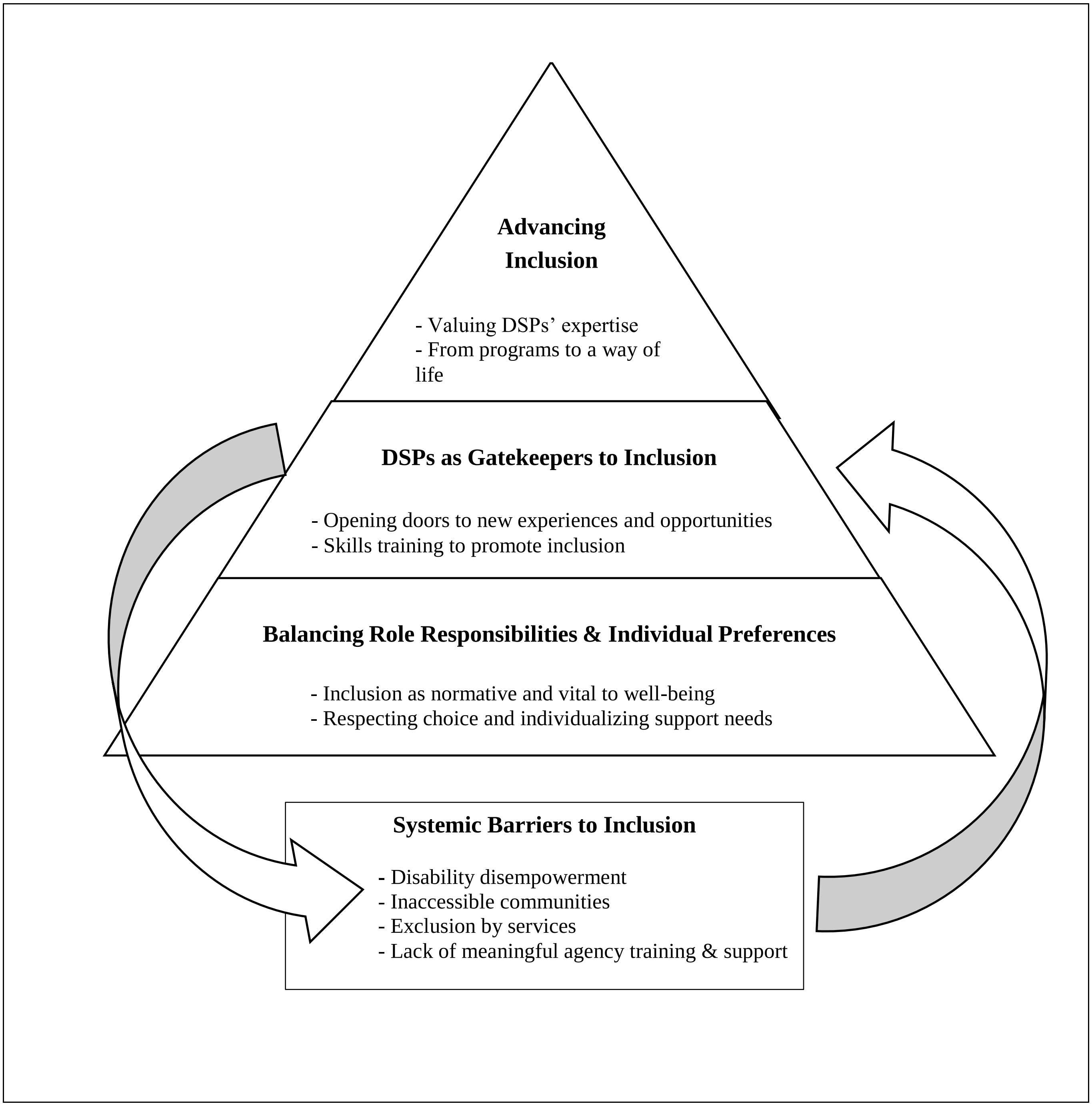

Table 1

Semi-Structured Social Inclusion Interview Guide

Interview Questions
How you describe social inclusion?
How important do you think it is for people with IDD to be included in their community?
In what ways does social inclusion impact the lives of people with IDD?
Is it part of your responsibilities as a DSP to help the people you support be included in the community? If so, how do you help the people with IDD be included across different settings/places?
What barriers or challenges have you encountered when trying to promote social inclusion for people with IDD?
How have you worked to overcome each of these barriers/challenges?
To what extent does your employer/agency talk about social inclusion or help to get people with IDD involved in the community in meaningful ways?
Is there anything else you would like to share or add about social inclusion for people with IDD?

Table 2

Respondent Demographics

Characteristic	**n (%)**
Gender	
Man	1 (4.8)
Woman	20 (95.2)
Race/Ethnicity	
White/ Caucasian	17 (81.0)
Black/ African American	4 (19.0)
Education	
High School Graduate/GED	3 (14.3)
Some College/ Post High School Certificates	4 (19.0)
Associate's Degree	3 (14.3)
Bachelor's Degree	9 (42.9)
Master's Degree	2 (9.5)
Work Setting	
Supported Living	12 (57.1)
Family Home	4 (19.0)
Group Home	3 (14.3)
Other (Community, Sheltered Workshop)	2 (9.6)

Note. (*N* = 21).

‘We need to be able to connect with people.’ Leveraging Direct Support Professionals’ Perspectives to Advance Social Inclusion

Dear Reviewers,

Thank you for the opportunity to revise and resubmit the manuscript. Every effort has been made to address the reviewers' concerns. Edits have been made accordingly and highlighted in the text of the manuscript. Thank you for sharing your time and expertise.

Reviewers' comments:

Reviewer #1:
Here are some minor issues related to APA7:
-Numbers should be in letters in this sentence: The interview
included 8 sociodemographic questions and 8 questions on social inclusion
-Quotations under 40 words should be incorporated into the text
-Block quotations should be double-spaced and no italic

Reviewer #3:
When discussing a super majority, I would connect the numbers of participants with the statistics you have listed under national norms on page 31 so the reader can easily reference it (without going back to the beginning).