From Exclusion to Inclusion and Gainful Employment – Understanding the Perspectives of Direct Support Professionals as they Support People with Intellectual and Developmental Disabilities

Jade Presnell
Faculty Mentor: John M. Keesler, PhD
Indiana University
School of Social Work

Author Note

Contact: jadepres@iu.edu

Abstract

Background: Social inclusion is an important quality of life indicator across the lifespan; however, people with intellectual and developmental disabilities (IDD) continue to experience significant exclusion as evidenced by high levels of loneliness and isolation, a lack of natural supports and social networks, and low workforce participation. Opportunities for social and workforce inclusion are often predicated upon having support from paid caregivers, typically Direct Support Professionals (DSPs). DSPs play an important role in supporting people with IDD; however, little is known about their experiences with inclusion.

Purpose: In an effort to identify new strategies for advancing social and workforce inclusion, the purpose of this study was to better understand DSPs' beliefs, attitudes, and experiences surrounding promoting inclusion for people with IDD.

Methods: Semi-structured interviews were conducted with 21 DSPs employed across three disability service agencies located in a midwestern state. A constructive grounded theory approach to qualitative analysis was used to identify categories across the data in response to answering the research questions.

Results: Analysis revealed four major categories (each consisting of two or more codes) across the data: "Balancing role responsibilities and individual preferences", "DSPs as gatekeepers to inclusion", "Systemic barriers to inclusion", and "Creating opportunities to advance inclusion".

Conclusion: DSPs held positive views on promoting inclusion for people with IDD. While they identified supporting inclusion as an important job responsibility, this was often limited to facilitating community presence and participation. DSPs face many systemic barriers that hinder their ability to effectively advance inclusion, especially in the workforce. Findings suggest that better equipping the direct support workforce with inclusion-specific resources and skills, and creating a more integrative, collaborative system of support for people with IDD has the potential to improve social and workforce outcomes.

Introduction

Approximately 42 million people in the United States (U.S.), or 12.7% of the population, have a disability (Erickson et al., 2019). It is estimated that 1.58% of the U.S. population has an intellectual or developmental disability (Krahn, 2019). Over the past 60 years, policies and services for people with intellectual and developmental disabilities (IDD) shifted from a philosophy of segregation to one of inclusion, bringing about the development of community-based services. Today, services focus on habilitation with an emphasis on the development of skills in areas of daily and community living, socialization, and selfcare (Division of Disability and Rehabilitative Services, 2016). As such, social inclusion is exemplified in the ideals and practices of independent living and integrated employment (Bigby, 2006; Officer & Groce, 2009; Ward & Stewart, 2008).

Disability services are primarily driven by paraprofessionals, specifically direct support professionals (DSPs) who provide much of the habilitative, direct care services and support to people with IDD. DSPs are often responsible for implementing individualized, person-centered support plans and assisting people with IDD in the pursuit of recreational, social and community activities based on their individual preferences. They provide support to people with IDD in a variety of settings (e.g., residential group homes, family homes, etc.) and often provide the day-to-day critical support that people with IDD need in order to be included in all aspects of society (National Alliance for Direct Support Professionals, 2022).

However, despite these services and supports, persons with IDD continue to suffer from high levels of social exclusion and isolation (World Health Organization [WHO], 2011). While there are more people with IDD residing in community homes, rather than in institutions or long-term care facilities, there remains a great disparity in social inclusion between adults with and without disabilities. As such, many people with IDD remain excluded and do not have meaningful opportunities to actively engage and develop social networks within their communities (Macdonald et al., 2018). Living in a community and living as part of a community are simply not synonymous.

One notable example of the social exclusion of people with IDD is their exclusion from the workforce. Alarmingly, less than 10 percent of people with IDD hold community-based, integrated employment (Hiersteiner et al., 2016). Notably, they also constitute approximately 14 percent of all working-age Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries (Livermore et al., 2017). Compared to other beneficiary groups, people with IDD face significant employment barriers. Consequently, they often rely on these federal benefits for much of their lives, keeping them marginalized and living in poverty. For example, many people with IDD work in segregated facility-based sheltered work settings making subminimum wage with few opportunities for vocational advancement or earning a livable wage (Siperstein et al., 2013).

The marginalization and exclusion of people with IDD continues to have widespread consequences for the disability community and broader society. Given this long-standing exclusion, continued efforts to understand effective strategies for promoting social and workforce inclusion for people with IDD are warranted. Therefore, a qualitative study was conducted to better understand the perspectives of DSPs in promoting social and workforce inclusion for people with IDD.

Background
Social Inclusion and Employment

Social inclusion is a multidimensional construct and results from a complex interplay between personal and environmental factors that increase a person's ability to contribute to society in a personally meaningful way. Social inclusion is defined as having full and equitable

access to activities, social roles, and relationships across settings (Cobigo, 2012) and is essential to the development and quality of life for people with IDD across the lifespan (Schalock, 2004). Being included in the community has been shown to be related to multiple positive outcomes, including increased social opportunities (McConkey et al., 2013), well-being (Azaiza et al., 2011), sense of belonging (Mactavish et al, 2000), skill acquisition (Siperstein et al., 2009), development of citizenship responsibilities (Ware et al., 2007), and most notably, employment (Taylor, 2020).

While the relationship between social and workforce inclusion for people with IDD is not fully understood, inclusion across both of these settings has been associated with positive psychosocial outcomes. Integrated employment for people with IDD has been positively associated with self-esteem, self-confidence, independence, self-determination, opportunities for choice making, and career progression (Almalky, 2020; Wehmeyer & Bolding, 2001) and increased earnings in comparison to participation in sheltered employment or day service programs (Butterworth et al., 2017). Being both included in one's community and at work are important quality of life indicators.

Beyond financial stability, participation in the workforce is an important part of life, as it increases opportunities for community engagement and building social networks and contributes to a sense of purpose and positive well-being (Graham et al., 2018; Kocman et al., 2018; Ottomanelli & Lind, 2009). In fact, the World Health Organization (WHO; 2011) has identified integrated employment as an important factor for promoting access to health, social, and community engagement and avoiding poverty for people with disabilities. Therefore, finding strategies to increase participation in the workforce is essential to improving the quality of life of people with IDD.

Role of Direct Support Professionals

Social inclusion and employment for many people with IDD is predicated upon having support from paid caregivers. The direct support workforce in the U.S. plays a critical role in supporting and promoting the well-being and advancement of people with IDD. DSPs play a myriad of roles in the lives of people with IDD, from assisting with skill building development to implementing person-centered support plans to connecting with community resources (President's Committee for People with Intellectual Disabilities Report to the President [PCPID], 2017). DSPs are often integral in facilitating access and participation for people with IDD across a variety of domains, including work, social supports, and citizenship responsibilities (PCPID, 2017); however, the extent to which they value inclusion and employment for people with IDD remains unknown.

Barriers to Social and Workforce Inclusion

Despite access to community-based habilitative services, there is ample evidence suggesting that many people with IDD continue to experience social exclusion and isolation (WHO, 2011). Although most people with IDD now reside in private or family homes in the community and participate in community activities with varying levels of support, physical inclusion has been insufficient for people with IDD to be accepted and fully included in the community (Scior et al., 2020). In fact, many people with IDD lack social networks, do not experience true participation in their community, and report higher levels of loneliness (Macdonald et al., 2018; Margalit, 2004; Sheppard-Jones et al., 2005).

Full social inclusion is impeded by multiple barriers. People with IDD have identified that having staff that do not support community participation is a barrier (Abbot & McConkey, 2006). DSPs may have a limited understanding of inclusion and instead focus more on community presence, rather than participation when it comes to facilitating social inclusion in the community (Clement & Bigby, 2008). Similarly, DSPs may be challenged with the idea of

social inclusion. While they indicate inclusion is important, they also suggest it may be too challenging for people with more severe intellectual disabilities (Bigby et al., 2009).

People with IDD also face disproportionate exclusion in the workforce as compared to people without disabilities (Petner-Arrey et al., 2016) and have the lowest rate of workforce participation as compared to those with other types of disabilities (Akram et al., 2020). It has been well established in the literature that people with IDD are capable of successfully maintaining integrated employment (Butterworth et al., 2017; Migliore et al., 2012; Wehman et al., 2014); yet continue to experience significant employment disparity. For example, employment rates for people with IDD have ranged from 18 to 23 percent in comparison to 76 to 79 percent for people without disabilities (Getzel, 2014). Of those with IDD who use SSI, only 8.2% are employed in the community (Winsor et al., 2018).

This is alarming considering research has indicated that many people with IDD desire self-sufficiency and indicate community-based, integrated employment as one of their primary goals (Migliore et al., 2007), yet they continue to experience pervasive barriers in achieving these goals. These barriers include, but are not limited to, individual factors (e.g., severity of the disability), employer characteristics, attitudes and misconceptions surrounding disability, stigma, and the quality of social supports (Akram, 2020). Central to improving employment outcomes for individuals with IDD is having access to reliable and quality supports (Nord, 2016). Various studies have found that DSPs play a critical role in determining the degree to which people with IDD are successfully included in their communities and the larger society (Overmars-Marx et al., 2014; Venema et al., 2015). Specifically, while much attention has been given to examining the role of job coaches in supporting people with IDD to obtain employment, DSPs are the ones providing the day-to-day support and who are responsible for assisting people with IDD in accessing and participating in their communities, building relationships with community members, and utilizing community-based resources- all essential prerequisites to entering the workforce.

The Research Gap

While little is known about DSPs' perspectives on promoting social and workforce inclusion for people with IDD, there is evidence to suggest these shape service delivery and outcomes. For example, DSP attitudes and beliefs have been found to influence what types of learning and social opportunities are available to those they support (Beckwith & Matthews, 1995). This is important, because DSPs with more positive attitudes toward inclusion and employment are more likely to facilitate activities that support these (Jones et al., 2008; Venema et al., 2018). However, more information is needed to better understand DSPs' perspectives surrounding their role and responsibility in promoting inclusion for the people they support.

Study Purpose

Given the important role that DSPs play in supporting people with IDD and the continued exclusion disproportionately experienced by people with IDD, both in the community and workforce, understanding DSPs' perspectives is critically important, as these have direct implications for quality of life indicators for people with IDD. Therefore, the purpose of this study was to better understand DSPs' beliefs, attitudes, and experiences surrounding promoting social and workforce inclusion for people with IDD in an effort to identify new strategies for advancing inclusion.

Research Questions

As such, this study sought to answer the following research questions:
- How do DSPs' describe their role and responsibilities in promoting social and workforce inclusion for people with IDD?
- What challenges exist in promoting social and workforce inclusion for people with IDD?

- How can disability providers better support social and workforce inclusion for people with IDD?

Methods

Research Design

This study used a qualitative research design as it aimed to describe the perspectives of DSPs regarding their role in promoting social inclusion and employment for persons with IDD. Exploring DSPs' subjective experiences, attitudes, and beliefs is best captured qualitatively, rather than statically (or quantitatively). Qualitative research is explicitly interpretative and focuses on meaning making. Specifically, a constructive grounded theory approach to quantitative analysis was used (Charmaz, 2014). This approach was most appropriate, as little is known about how DSPs describe their role in promoting inclusion.

Data Collection

Following approval by the University Institutional Review Board, three disability service agencies agreed to participate in the study. These agencies were suitable sources for recruiting participants as they have long histories of serving people with IDD, a large pool of DSPs, and are committed to community inclusion for people with IDD. Purposive/selective sampling was used as this study aimed to specifically explore the unique perspectives of DSPs. In order to be eligible, respondents had to have been employed full-time with their respective agencies for at least 6 months. Upon approval from agency stakeholders, respondents were recruited via agency email listservs. DSPs were presented with a recruitment email and asked to reach out directly to the researcher to participate. Recruitment spanned over a period of 6 months.

Data were collected via interviews between the researcher and DSPs. Respondents were asked to participant in an audio recorded interview via Zoom. On average interviews took approximately one hour. A semi-structured interview guide approach was used. This guide was developed by the researcher via consultation with the literature on inclusion and an expert researcher in the field. The interview guide included 8 sociodemographic questions and 16 questions on social and workforce inclusion and included questions, such as "What barriers or challenges have you encountered when trying to promote social inclusion for people with IDD?" and "How have you supported people with IDD with reaching their employment goals?" (see Appendix 1 for the full list of questions). Notably, respondents were first asked to describe social inclusion in their own words and were then provided with the definition of social inclusion by Cobigo (2012) in order to strengthen the validity of responses. All respondents were provided with a $20 gift card for their participation in the interview.

Data Analysis

All interviews were transcribed and analyzed using constructive grounded theory (Charmaz, 2014). Consistent with grounded theory, analysis emerged from an inductive approach and iterative process in which the researcher went back and forth between 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 as needed following the interviews and during analysis to record the researcher's thoughts and ideas. Open coding, in which conceptual labels are created to identify information as it emerged from the data, was used. A constant comparative method was used between the data, codes, and memos 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 and how these can improve service provision. Notably, 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 research questions.

Additionally, several strategies consistent with the grounded theory framework were used to increase the trustworthiness, credibility, and rigor of this analysis. These included: maintaining a detailed audit trail of all research activities (Lincoln & Guba, 1985), maintaining a reflexivity journal to explore and examine researcher positionality throughout the research process (Charmaz, 2014), and conducting periodic member checking with respondents to review aspects of the interpretation of the data and assess for accuracy (Creswell & Miller, 2000).

Participants

Twenty-one DSPs employed across three disability service agencies located in a midwestern state participated in the study. Descriptive statistics for respondent demographics can be found in Table 1. 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 ($SD = 13.83$). Nearly half indicated they held a bachelor's degree (42.9%). Most respondents indicated that they did not hold any additional responsibilities outside of being a DSP within their agency; however, 5 of the DSPs held additional roles (e.g., trainer, team leader, etc.). The majority reported working primarily in supported living sites or family homes (76.1%). On average respondents reported they had been working with their respective agencies for nearly 9 years ($M = 8.79$, $SD = 8.62$), which was similar to the average numbers of years working as a DSP ($M = 9.76$, $SD = 7.30$). Notably, total years working as a DSP ranged from 1 to 30 years.

Results

Across the data four major categories emerged from the codes: "Balancing role responsibilities and individual preferences", "DSPs as gatekeepers to inclusion", "Systemic barriers to inclusion", and "Creating opportunities to advance inclusion". These categories and their codes are shown in Table 2. A description of each category and the corresponding codes is subsequently presented. Each code is illustrated by quotes from the DSP interviews.

Balancing Role Responsibilities and Individual Preferences

This category describes DSPs beliefs on social and workforce 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 respondents described social inclusion as important for a good quality life. In fact, most respondents described being socially included across settings as "very important" and even "vital" to wellbeing. Notably, DSPs consistently identified supporting social inclusion as an important part of their role responsibilities. The experience of social inclusion was associated with multiple benefits, such as improved self-esteem, having more friends, and protection against mental health conditions (e.g., depression). Supporting social inclusion was frequently described as having a presence in the community- for example, eating out at restaurants, going grocery shopping, or attending activities specifically intended for the disability community, such as Special Olympics. Other examples of DSPs supporting social inclusion included attending concerts and festivals, visiting parks and museums, volunteering, and helping to plan date nights.

While the majority of respondents indicated that it is not a part of their role responsibilities to help people with IDD obtain employment, all indicated they believed people with IDD can hold meaningful jobs in the community and that workforce participation is valuable. Similarly, all noted the various benefits of workforce inclusion that extend beyond earning a paycheck, such as increased self-sufficiency and sense of empowerment, expansion of one's social support network, and feeling a sense of pride and accomplishment.

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)

Respondents often equated promoting social inclusion with providing people with IDD the full range of opportunities and experiences to live a "normal life". As such, the desire to be socially included was considered to be a fundamental human need and normative experience. Many asserted that people IDD should not be denied typical life experiences, such as grocery shopping, eating out, or having a job. One respondent described supporting employment goals as important, because having a job is a "fundamental part of life".

To be included is to be exposed to everyday life. And as normal as the fashion as possible. (Respondent 4)

Okay, because we're all human beings, and to not be able to experience a certain realm, you know, a certain part of the life experience that, that is just not good in my, you know, in my opinion. (Respondent 2)

The majority of respondents indicated there weren't any situations in which they felt like people with IDD could not be included unless the activity or environment was physically inaccessible preventing participation. Further, several respondents reported that opportunities for both social and workforce inclusion are often limited for those with physical disabilities and those with high support needs.

Respecting Choice and Individualizing Support Needs. Even with the emphasis on promoting social inclusion, many respondents acknowledged that people with IDD- like others- have varying preferences for social interactions and activities. For example, respondents indicating respecting people's choice to *not* participate in activities. Respondents also described the unique personalities and strengths of the people they support, as well as the wide range of individual preferences for activities from visiting the library to taking vacations to going to the casino.

DSPs generally felt similarly about workforce participation for people with IDD, indicating work as an individual choice, and that support teams should respect people's choice as to whether or not to pursue employment. This was especially true for those respondents who support aging adults. Many suggested that older adults who are nearing "retirement" age should not be forced to participate in programs (e.g., day services or sheltered workshop) if they choose not to. Ultimately, respondents asserted that in order to successfully promote inclusion across settings, DSPs must respect individual choice and preferences for how and to what degree people with IDD want be included.

I let the clients choose. If they don't know then I'll offer options. But I let them choose. (Respondent 7)

And I think that's an important thing to remember too is that not everybody wants a job but those people who do want a job should be allowed the opportunity to go do that. (Respondent 9)

Many respondents also normalized the need for support and asserted that the degree and type of support each person needs varies considerably. For example, some people benefit from

having DSPs participate alongside them in activities (e.g., co-volunteering), whereas others need less intense support, such as positive praise and encouragement or transportation assistance to and from activities/events. As such, the support provided to each person with IDD is individualized and takes into consideration various factors, including functionality, 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. So, she kind of just broke it down where we're all people, doesn't really matter how much support we need, that we all should be included in everything. ...We all need a little support. They [people with IDD] just need a little bit more than we do… What I like about the organization I work with is every, all, 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, but especially to the community. As such, DSPs play a pivotal role in helping those with IDD access and participate in community experiences and relationships, as well as in 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".
    Opening Doors to New Experiences and Opportunities. Outside of meeting transportation and personal care needs, DSPs most often reported promoting social inclusion by sharing ideas, encouraging participation, and aiding in accessing opportunities. Many identified supporting social inclusion by "generating ideas" of activities, such as watching fireworks or attending community events. Others identified that they encouraged participation in new activities as a way to expand people with IDD's interests and experiences.

> *Trying to find opportunities, trying to educate people. And just trying to be successful as we can be trying to get that those doors opened.* (Respondent 17)

> *Beyond the goals of each individual to find things that they really want to engage in and that they are in then and develop their hobbies and interests and not necessarily my own or just places that 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)

    Many pointed to the degree of "planning" that is required to help people with IDD participate in their communities, especially when faced with accessibility (e.g., lack of transportation) and staffing (e.g., lack of staffing) barriers. Respondents took various steps to open these doors, such as requesting a discounted price to events/activities, arranging accessible transportation, educating community members to be more accepting of those with IDD, and making accommodations for successful participation. Respondents also frequently identified that the presence of DSPs can help people with IDD feel more confident and secure in navigating new experiences and overcoming "social anxiety".
    Additionally, while the majority of respondents indicated not being responsible for providing employment support, many identified that DSPs could be helpful in creating new workforce opportunities by sharing job postings with the people they support, advocating that

more employers hire people with IDD, and supporting people in exercising their right to accommodations.

> *I think it's very important they [people with IDD] have every right and responsibility. That they're able to do what they want and have supports if they're not able to do it on their own. That they have a job coach or a DSP that can be there to help them do what they need to do.* (Respondent 16)

Skills Training to Promote Inclusion. With the emphasis on being in the community, all respondents reported that it was their responsibility to provide a variety of supports to assist people with IDD in being socially included ranging from social skills training to advocacy to participating in community activities alongside those they support. Many respondents made note that people with IDD may experience challenges with recognizing and following social norms, which can interfere with building relationships, as well as work and community participation. DSPs shared that are expected to provide the training, coaching, and modeling that will help people with IDD successfully navigate social situations and settings, as well as demonstrate increased independence. For example, respondents expressed helping to support inclusion in the community through teaching and coaching in the areas of communication, problem solving, conflict resolution, and social skills.

> *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)

In regard to promoting inclusion in the workplace, respondents most often indicated providing transportation support to and from work. However, DSPs also reported that while they rarely provide direct support with employment goals, they often provide peripheral support that helps people with IDD maintain their jobs, such as coaching in the areas of hygiene (e.g., wearing clean clothes to work), appropriate workplace behavior (e.g., how to interact with coworkers), work preparation (e.g., having a lunch packed), and self-care (e.g., dressing appropriately for the weather).

> *They need acceptance, they need educated employers. Certain ones need the assistance, they need aides. And they need aides that are willing to assist these individuals but not make them feel quote unquote 'dumb' for needing assistance.* (Respondent 6)

Systemic Barriers to Inclusion

Category three describes the macro and mezzo level barriers that DSPs face when trying to promote social and workforce inclusion. These barriers were most often described as attitudinal, physical, and systems-oriented in nature. This category has four codes: "disability disempowerment", "inaccessible communities", "exclusion by services", and "lack of meaningful agency training and support".

Disability Disempowerment. Respondents shared varying experiences surrounding their interactions supporting people with IDD in the community. While many shared positive community experiences, there were also many accounts of how disempowering perspectives of disability held by others can act as barriers to inclusion. Many DSPs reported experiencing negative attitudes and "judgment" when interacting with community members. For example, one respondent recalled an incident in which they were harassed by a restaurant patron due to the

person they support "drooling" while eating. Respondents indicated that people with IDD are not always welcomed or accepted in certain activities or spaces.

> *I've noticed even like when people, when they 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)

Similarly, respondents overwhelmingly pointed to the reality that low expectations and inaccurate assumptions surrounding the capabilities and contributions of people with IDD in the workplace are significant barriers to employment. For example, potential employers may underestimate the skills and overestimate the degree of support needed for people with IDD to be successful in community-based employment.

> *It's hard to find places that will hire people with IDD. It's not supposed to be but hire someone to do something other than like cleaning or wrapping silverware, or basic things like that. It would be nice if we could get them to do something else. And a lot of people with IDD work in like, fast food. I have like three clients in fast food but that's not a good fit for them, because that's fast paced, and they need more time to process what they're doing. So, I think finding a better fit would be something that would be really helpful.* (Respondent 7)

In fact, people with IDD's opportunities for employment seem to be limited to certain industries, such as fast food and janitorial work. One respondent described this as putting people with IDD's options for jobs "in a box", rather than exploring the full range of employment opportunities available.

> *And so, automatically when people see somebody with a disability, they're automatically going to assume that this person is going to need such and such assistance. And sometimes that's not true, sometimes an individual is very high functioning, and they don't, they're not going to need much assistance. And then you're going to have some individuals that are going to need one-on-one aids. And I just, I think that socially people don't understand that. And they just automatically assume and so again education is just like a big thing." "Like I know that a lot of places are like we don't discriminate based on disability blah blah blah, but they definitely do it. They definitely do.* (Respondent 6)

Inaccessible Communities. DSPs also identified inaccessibility as an ongoing challenge that limits where people with IDD can go in the community and what activities they can participate in. DSPs frequently reported that many community settings do not accommodate people with IDD in relation to their physical, sensory, and communication needs. For example, community spaces, such as stores or restaurants may be loud or crowded, which can create challenges for those with sensory-related sensitivities. Additionally, these settings may not accommodate the needs of those who use adaptative equipment, such as wheelchairs. In fact, many respondents identified that their agencies did not have accessible transportation easily available for those who use wheelchairs.

> *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)

Similarly, many respondents noted they believed that potential employers have not taken advantage of advancements, like assistive technology to create more inclusive workplaces. This is especially true for people with IDD who are non-speaking and often face significant barriers in finding workplaces that are accommodating to the use of alternative communication methods. Some respondents, however, noted that many accommodations for people with IDD (e.g., more frequent breaks) can often be made fairly easily, but that employers must be willing and motivated to provide these.

> *People are able to work, and if they want to work, they should be given the option of working and every company should do everything possible to help them. Whether it's a DSP with them the whole time or it's an Apple Watch or an extra sensory break because they need an extra break during that eight hour shift.* (Respondent 16)

Exclusion by Services. DSPs identified multiple systemic, service-level barriers to promoting social inclusion. The most frequently cited were high staff turnover, lack of funding to support inclusion across settings, especially the workplace, and being told that supporting employment is not a part of their responsibilities as a DSP.

Due to high staff turnover and limited staff availability, DSPs reported that people with IDD are often left with limited support. They described instances in which there was not enough staffing available for people to participate in preferred activities or alternatively, people with IDD were asked to participate in non-preferred activities due to having to share support staff with housemates. DSPs acknowledged that fully supporting inclusion for multiple people with IDD is often further hindered by service-related budgetary constraints that prevent them from having additional support across settings, especially in the workplace. For example, multiple respondents mentioned that job site support is not provided by DSPs, because it is too "costly". Notably, people with IDD living in group homes and those with Legal Guardians appeared to be disproportionately impacted by these systemic barriers, and according to DSPs were often subjected to more restrictions and fewer opportunities for inclusion.

> *.. 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)

Additionally, nearly all respondents reported they were generally discouraged from or explicitly told not to provide employment support. DSPs consistently shared that outside of providing transportation, employment support was not a part of their job responsibilities. The most often cited reason for this was that this support should be provided by an employment consultant or "job coach". However, of twenty-one respondents, only two reported having any experience working with a job coach. Similarly, many reported having little experience providing job-related support and little knowledge of the employment services offered by their agencies.

> *If I had one complaint about [names agency], it would be the micromanaging that is involved, because I did have a client who was wanting a job. And he was wanting a job at a particular place. I was going to go take him and help him get the application filled out and everything and I was told that I absolutely could not do that, because that is all handled by the job coaches in that department. So, they wanted me to do nothing at all.* (Respondent 5)

I just got lucky. Let's just say I got lucky that a good job coach that was willing to work with me… That was the only job coach that I have ever interacted in. And like I said, I just got lucky that she listened to me, and we worked together. (Respondent 13)

Despite this, many respondents believed that DSPs could in fact provide meaningful employment support if given the opportunity, such as by assisting with completing applications, finding job opportunities, providing input to the employment consultant on skills and goodness of fit with jobs, and educating and networking with community employers to advocate for more inclusive employment opportunities.

Lack of Meaningful Agency Training and Support. Most respondents indicated they felt their respective agency was "doing its best" to support inclusion; however, overwhelmingly, DSPs reported having received little to no training on *how* to support inclusion in a meaningful way. Issues surrounding staff competency were sometimes cited as a barrier to inclusion- such that some staff did not feel comfortable taking people out into the community due to the severity of their disability or behavioral challenges. Some respondents also noted that the staffing crisis has comprised the quality of training being provided to DSPs, especially during the onboarding process, such that some DSPs are ill prepared to provide support in the community.

Okay, you know, I'm the only one that takes her out. No, no one else feels secure doing that. Um, she has in the past been known to be aggressive when she's trying to communicate and isn't understood. And that's exactly what it is. Or she's wanting something and being ignored, and her form of aggression is grabbing you. (Respondent 4)

I think just like, training is a huge factor that would definitely help and all that. Just trying to have the time to be able to kind of guide people or, you know, spend time with them before they are just kind of thrown in. (Respondent 3)

Well maybe work with the staff that is reluctant to do that [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. You know how to make it easier and more comfortable for them. If they're comfortable with it then they'll do it… So, I think if they talk to them more and really kind of talked about it more specifically, and how to make it work maybe that would be a good thing. (Respondent 9)

Further, when training surrounding inclusion *was* provided it was generally focused on health and safety. For example, DSPs were often trained on how to intervene and de-escalate if a person they support began experiencing a behavioral health crisis in the community. Training also focused on teaching DSPs how to respond to potential medical emergencies in the community, such as supporting someone during a seizure. Additionally, many reported that their agency did not provide any resources to support inclusion with the exception of access to transportation support (e.g., agency vans) and occasional tickets to community events.

Creating Opportunities to Advance Inclusion

The fourth and final category builds off of DSPs existing strengths and knowledge to create opportunities to advance inclusion for people with IDD. Feedback from DSPs suggests that new opportunities for inclusion could be realized by more fully utilizing the expertise of

DSPs through collaboration and feedback and moving beyond programming to embrace 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. Nearly all respondents discussed how valuable their role is in supporting the overall wellbeing of those they support. They described having intimate knowledge surrounding how best to support people with IDD- for example, by recognizing and avoiding triggers to behavioral challenges, understanding alternative forms of communication, and knowing individual preferences. Many also referred to the important advocacy work they carried out in an effort to help people with IDD experience inclusion.

> *.... I think having a support person or DSP enables them to live a fuller life and have all of the possibilities available to them.* (Respondent 16)

> *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… And if it's just not happening, then we'll just regroup and take a break.* (Respondent 16)

> *You know, it's always been something that I work for a lower pay than what I know I'm worth. But I like my job and the job rewards of my job are not necessarily just monetary. I've built relationships with people, and I'm in the disability community as an advocate.* (Respondent 16)

However, despite this expertise, DSPs identified rarely being involved in the person-centered planning process for the people they support. For example, they reported that team members rarely seek out their input or consult with them on support needs, goals, or progress. They also frequently reported being excluded from participation in teaming meetings and case planning. Yet, they acknowledged that an important part of the DSP role is to adhere to and execute person-centered support plans in an effort to assist people with IDD in reaching their goals. As one respondent put it, "They're just telling us what to do." Collectively, respondents expressed that it would be beneficial if DSPs had more of a "voice" in service planning and delivery.

> *You have to be careful as a DSP that we're not overstepping boundaries. You might know this client with your eyes closed and know what's best for them. And then when you try to suggest something, you have to be careful, because people there a little over us might think they know better.* (Respondent 13)

From Programs to a Way of Life. When asked about how their agency supports inclusion, respondents most often identified their agency as having inclusion "programming". The programs most often identified were 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, sports, etc.). Interestingly, many respondents considered participation in events (e.g., prom) and programs (e.g., day programs and sheltered workshops) specifically for people with IDD as examples of social inclusion. Respondents often referred to social inclusion as both a service and an outcome for people with IDD.

> *Also, my agency is big on you know 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 so. (Respondent 6)

*…I think for most people that is part of it, the whole idea of the Medicaid waivers and the community living, um the community integration…So, the whole point of that is to get people with, you know, IDD and developmental disabilities included in the community. (*Respondent 9)

However, as mentioned, many respondents also referred to the desire to be included as a fundamental human need that, when fulfilled, contributes to positive social and identity development. Similarly, DSPs also asserted that people with IDD should be "given a chance" to be included and have access to accommodations, so that they can participate in all aspects of society. Some held perspectives on promoting inclusion that extended beyond events and programs to inclusion as a personal experience that encompasses a sense of belonging and connectedness, as well as a means for building social capital and self-efficacy.

Working as a DSP I like, I like it when, you know, that clients feel a part of where they're at. So, I don't know, it just, it makes my heart happy to see that they actually can feel included, and in people's lives that they normally wouldn't meet otherwise….When people, you know, when we go to the store, when we go to the same store all the time, we get to know people. It's a part of our circle. And whether they go the same bank or whether they go to, you know, they, they go to the same restaurant all the time. If they have a rhythm in that and they get to know people and you never know who you're connecting with. We want to get to all these different places and they're connecting with all these people. And that, that can have an impact on their lives and they're going to have an impact in their life. So, and that's very important to have because, you know, what we all, even without IDD, we need that social capital. We need to be able to connect with people. (Respondent 8)

Discussion

In an effort to identify strategies for advancing social and workforce inclusion for people with IDD, the present study explored DSPs perspectives and experiences surrounding promoting inclusion. Overall, DSPs indicated highly valuing inclusion across settings- although they acknowledged that much of the support they provide advances social, rather than workforce inclusion. DSPs asserted that inclusion across settings has many benefits in helping people with IDD to live self-directed, meaningful, and socially connected lives. In addition to recognizing the immense benefits of being included, they also pointed to the macro-oriented, systemic barriers that often get in the way of people with IDD experiencing inclusion (e.g., a lack of meaningful agency support, training, and resources to promote inclusion) that point toward new solutions for creating more inclusive communities.

Research Question 1

When exploring DSPs' responsibilities for advancing inclusion, respondents 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 (2008) 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) describes 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 additional training and guidance from agencies in developing the skills to assist the people they support to develop meaningful relationships with others in their community (e.g., neighbors, business owners).

Additionally, DSPs asserted that with the appropriate support and accommodations people with IDD *can* successfully be 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 their communities 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 as those with more severe disability should not be excluded from experiencing the psychosocial benefits of inclusion.

Contrary to their experiences supporting social inclusion, DSPs reported very little interaction with or knowledge of employment services both within and outside of their agencies. In fact, DSPs overwhelmingly reported that supporting employment goals was not a part of their job responsibilities. Yet many believed that their input, support, and coaching could be valuable in helping people with IDD explore job opportunities, complete job applications, network with potential employers, and build vocational skills. Many DSPs expressed a willingness to provide more direct employment support if given the opportunity. Given the very low workforce participation rates for people with IDD (Akram et al., 2020) it is essential that agencies consider how DSPs can use their unique skills and knowledge to become more involved in supporting vocational goals.

Research Question 2

When exploring what challenges exist in promoting social and workforce inclusion, DSPs identified encountering a number of 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 disability community, they also reported experiencing microaggressions while supporting people with IDD in the community.

Specifically, they identified a lack of acceptance, negative attitudes, and low expectations toward people with IDD as significantly limiting opportunities for community and workforce participation. When assessing compatibility with various roles (e.g., employee, volunteer) DSPs noted that people with IDD are often evaluated based on perceived functionality. For example, prospective employers may not consider hiring people with IDD due to assumptions about their "level of functioning" and support needs. These experiences are consistent with research identifying stigma and discrimination toward people with IDD as driving forces of exclusion (Scior, 2020). Therefore, it is important moving forward that DSPs are equipped by their agencies in responding to and challenging these types of ableist encounters that limit opportunities for inclusion.

Notably, the influence of systemic barriers on hindering inclusion is exemplified in the social model of disability. The social model of disability recognizes the impact of social structures and attitudes on people with IDD and emphasizes inclusion, choice, and well-being (Kimberlin, 2009). This paradigm suggests that it is not disability itself that limits people with IDD's full and equal participation in society, but rather societal beliefs and stereotypes surrounding what it means to be 'disabled'. Hence, there is less emphasis on improving the functional limitations associated with disability and more attention on changing attitudes, cultural norms, and structures to make society more accessible and inclusive (Oliver & Barnes, 2010).

Shifting from a needs-based to social model of disability would provide disability agencies with a stronger framework for advancing inclusion, as the focus would be on creating systemic, macro-level change to support the development of more inclusive communities. This model also emphasizes the responsibility that disability agencies have in challenging 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 DSPs.

Research Question 3

Considering these barriers, it was also important to explore how disability agencies and DSPs can better support inclusion. Positively, DSPs expressed favorable attitudes toward their work supporting people with IDD and believed their role to be influential in the lives of those they support. Many shared having intimate knowledge of people's preferences, progress toward goals, and support needs. Despite this expertise, many DSPs indicated little involvement with team collaboration or person-centered planning. They often expressed feeling devalued and underutilized by agency leadership, especially in the area of employment support. If progress is going to be made toward inclusion, DSPs must have a voice in person-centered planning and service planning and delivery.

Additionally, many DSPs believed their agencies were supportive of inclusion, because of the programming they offered. However, there was also the indication by some DSPs that inclusion cannot be fully captured or achieved via a service or program, but rather should be embraced as a way of being in the world that contributes to living a good life. Shifting from inclusion as programming to inclusion as a value and way of life is a necessary step in advancing inclusion. This will require agencies to critically evaluate how well their services, policies, and practices align with the philosophy of inclusion.

Implications

These findings have several key implications for improving service delivery and policy to advance social and workforce inclusion for people with IDD. First, disability agencies must better equip DSPs with the tools, resources, and training to effectively assist people with IDD in being included across settings. DSPs should feel supported by their agencies, especially leadership, and have the tools to feel confident and effective in their role. This training should extend beyond ensuring health and safety to providing DSPs with the skills to support people with IDD at all levels of need, respond to and navigate macro barriers to inclusion, and become more effective advocates. Further, while an emphasis on health and safety is beneficial, it may directly conflict with promoting inclusion. Oftentimes new experiences involve some level of risk; therefore, DSPs must have the support from leadership in helping people with IDD pursue new experiences. Similarly, agencies must provide DSPs with the necessary resources to support inclusion, such as accessible transportation, well trained DSPs, and adequate staffing coverage to ensure disability agencies are not creating additional barriers to inclusion.

Second, disability agencies must critically evaluate the degree to which their services and policies are effectively advancing inclusion. This means considering how *all* agency roles can work together effectively to improve the quality of life of people with IDD. Creating more collaborative, egalitarian cultures within agencies will create new opportunities for DSPs to utilize their expertise to help people with IDD to have more equitable access to activities, roles, and relationships in their communities. This will also require that agencies be more intentional about guiding support teams on how to work together to promote inclusion and overcome barriers. Employment consultants/job coaches in particular should engage in regular collaboration with DSPs to gather information related to interests, strengths, skills, and support needs, as well as to provide DSPs with guidance on how they can best support vocational goals.

Finally, collectively, the disability service sector would benefit from using the social model of disability as a paradigm for service delivery. Moving away from a needs-based model of service delivery would shift the focus away from individual impairment as a barrier to inclusion to addressing the systemic barriers that prevent people with IDD from experiencing inclusion. While agency-directed programs may offer some important opportunities for inclusion, additional work to target barriers at the macro and mezzo levels (e.g., community outreach to change attitudes toward disability) is necessary and would result in more sustainable change efforts toward building inclusive communities.

Implications for the Social Security Administration. These findings also point to strategic implications for the Social Security Administration (SSA) aimed at reducing the employment disparity for people with IDD. Notably, SSA assists beneficiaries with disabilities, including those with IDD in reaching employment goals through the Vocational Rehabilitation (VR) Reimbursement Program. Vocational Rehabilitation is a program jointly funded by the federal government and states and territories. If eligibility is met, people with IDD who are unemployed or underemployed can access these services and receive assistance from a Vocational Rehabilitation Counselor (VRC). The VRC then works with individuals to create an individualized employment plan that highlights the steps toward employment, including identifying employment-related goals, the services and supports needed to achieve these and who is responsible for providing these, and how progress will be evaluated. This support can include assistance from an employment consultant/job coach who can provide the necessary coaching and support to help people with IDD obtain or maintain employment in the community. The employment consultant/job coach oftentimes assists with directing job search activities, developing a resume, practicing interviewing techniques, and providing on-site support as needed (Family and Social Services Administration, 2022).

Results indicate that despite the significant role DSPs play in supporting inclusion, at present their expertise and support is rarely utilized in the area of workforce inclusion. Overwhelmingly, DSPs held favorable attitudes toward supporting inclusion across all settings, especially the workplace, but identified having little contact with or knowledge about existing vocational services through VR or employment services within their own agencies. Most DSPs also had little to no experience working with an employment consultant/job coach, but acknowledged possessing valuable knowledge that, if utilized, could be helpful in facilitating progress toward employment for those they support.

Specifically, there are several strategies VR can employ to improve workforce outcomes. (1) VR can work to increase DSPs knowledge of SSA benefits and VR services and processes through webinars and trainings. (2) Employment consultants/job coaches should ensure that employment goals are included in person-centered support plans, so that all members of a support team are aware that the individual is involved with VR. Additionally, these plans should identify what specific vocational support/training is needed (e.g., interview etiquette) and how

this can be facilitated by DSPs across settings. (3) VR should engage and collaborate with DSPs during every step of the process from assessment to job placement in order to gather more accurate data and track progress/outcomes. (4) Finally, VR would benefit from working alongside direct support staff to determine how support from DSPs can be utilized and strengthened to improve outcomes, particularly as VR support fades and DSPs remain involved with supporting the individual at home and in the community.

If real progress is to be made, home and community-based services and employment services for people with IDD within states cannot continue to be siloed. Creating a system of supportive services that is integrative, and collaborative would offer increased opportunities for support across settings (e.g., home, community, work) to be well-coordinated, thereby increasing accessibility to services, improving outcomes, and reducing associated costs. Ideally, people with IDD and their families, DSPs, VCRs, and employment consultants/job coaches would work together to share and utilize their expertise, knowledge, skills, and training to advance workforce inclusion for people with IDD. This collaboration seems particularly relevant and necessary given the barriers to inclusion identified by DSPs, such as high staff turnover and a lack of funding, which can lead to gaps in or an absence of services and support.

Limitations

While this research illuminates how social and workforce inclusion can be advanced for people with IDD based on DSPs beliefs and experiences, it does so with limitations. Notably, the limited sample of twenty-one DSPs poses questions surrounding the transferability of findings to other respondents and contexts. For example, all respondents worked with disability service agencies who had long histories of serving people with IDD in their respective communities. Oftentimes, respondents reported that opportunities for inclusion were enhanced as a result of the agency's partnership with various community organizations (e.g., churches, volunteer organizations). As such, it is unclear whether DSPs employed with newer agencies will have similar perspectives on and experiences with inclusion. Similarly, respondents in this study had on average 10 year of experience working as a DSP. This is atypical of the DSP role; therefore, it is possible that DSPs with less experience in the field might hold different perspectives on inclusion.

Notably, even with the provision of an incentive, it was difficult to obtain participants. It is possible that interest in the study was low or that DSPs were hesitant to participate considering that recruitment messages and emails were filtered through the agency. Additionally, many in the direct care workforce are experiencing fatigue and burnout (Keesler, 2020)- all of which has been exacerbated by the impact of COVID-19.

Finally, the use of triangulation could enhance the validity of the findings. The present findings represent the perspective and experiences of DSPs and therefore may not reflect the experiences of other stakeholders. Gathering additional input from agency leadership and people with IDD receiving support would help to better contextualize and strengthen these findings.

Conclusion

Overall, DSPs held positive views on promoting inclusion for people with IDD. While they indicated supporting inclusion as an important job responsibility, this was often limited to facilitating community presence and participation. At present, DSPs do not appear to be taking active roles in helping people with IDD be included in the workforce. DSP involvement in promoting workforce inclusion is often hindered by organizational culture and programing structures within disability agencies that exclude DSPs from involvement in important activities, such as person-centered planning. The findings from the present study suggest that DSPs remain an underutilized resource for advancing social and workforce inclusion for people with IDD.

Efforts must be made across the disability service sector to enhance the degree to which agencies train, support, and equip DSPs to advance social and workforce inclusion.

References

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, *10*, 275-287. https://doi.org/10.1177%2F1744629506067618

Akram K.M, Wittevrongel, K., Nicholas, D.B. & Zwicker, J.D. (2020) Prioritizing barriers and solutions to improve employment for persons with developmental disabilities, *Disability and Rehabilitation*, 42:19, 2696-2706, DOI: 10.1080/09638288.2019.1570356

Almalky, H. A. (2020). Employment outcomes for individuals with intellectual and developmental disabilities: a literature review. *Children and Youth Services Review*, *109*, 104656.

American Association on Intellectual and Developmental Disabilities. (2019). *Definition of intellectual disability*. https://www.aaidd.org/intellectual-disability/definition

Azaiza, F., Rimmerman, A., Croitoru, T., & Naon, D. (2011). Participation in leisure activities by Arab adults with intellectual disabilities living in the community. *International Journal of Social Welfare*, *20*(1), 97-103. https://doi.org/10.1111/j.1468-2397.2009.00703.x

Beckwith J. B. & Matthews J. M. (1995). Measurement of attitudes of training professionals to people with disabilities. *Journal of Intellectual Disability Research 39*, 255–62. https://doi.org/10.1111/j.1365-2788.1995.tb00517.x

Bigby, C. (2006). Shifting models of welfare: Issues in relocation from an institution and the organization of community living. *Journal of Policy and Practice in Intellectual Disabilities, 3*, 147–154. https://doi.org/10.1111/j.1741-1130.2006.00074.x

Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). "It's pretty hard with our ones, they can't talk, the more able bodied can participate": Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research, 53*, 363–376. https://doi.org/10.1111/j.1365-2788.2009.01154.x

Butterworth, J., Christensen, J., & Flippo, K. (2017). Partnerships in employment: Building strong coalitions to facilitate systems change for youth and young adults. *Journal of Vocational Rehabilitation*, *47*(3), 265-276.

Charmaz, K. (2014). *Constructing Grounded Theory* (Second Edition). Thousand Oaks, CA: Sage

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.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*(3), 124-130. https://doi.org/10.1207/s15430421tip3903_2

Ericks on, W., Lee, C., & von Schrader, S. (2019). *2017 Disability Status Report: United States.* Ithaca, NY: Cornell University Yang-Tan Institute on Employment and Disability (YTI).

Family and Social Services Administration. (2022). *Vocational Rehabilitation/Employment*. https://www.in.gov/fssa/ddrs/rehabilitation-employment/vocational-rehabilitation-employment/

Friedman C. (2018). Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 56*(4), 234–250. https://doi.org/10.1352/1934-9556-56.5.234

Glaser, B. G., & Strauss, A. L. (1967). *Discovery of grounded theory: Strategies for qualitative research*. Routledge.

Graham, C., Inge, K., Wehman, P., Seward, H. & Bogenschutz, M. (2018). Barriers and facilitators to employment as reported by people with physical disabilities: An across disability type analysis. *Journal of Vocational Rehabilitation*, 48(2), 207–218. doi:10.3233/JVR-180929

Getzel, E. E. (2014). United States congress, senate committee on health, education, labor and pensions: Introductory remarks. *Journal of Vocational Rehabilitation*, *40*, 183–184.

Hiersteiner, D., Bershadsky, J., Bonardi, A., & Butterworth, J. (2016). Working in the community: The status and outcomes of people with intellectual and developmental disabilities in integrated employment--Update 2. *NCI Data Brief*. Cambridge, MA: Human Services Research Institute.

Indiana Health Coverage Programs. Division of Disability and Rehabilitative Services. (2019). *Home and Community-based Services Waivers* (Version 7.0). https://www.in.gov/medicaid/files/ddrs%20hcbs%20waivers.pdf

Jones J., Ouellette-Kuntz H., Vilela T. & Brown H. (2008). Attitudes of community developmental services agency staff toward issues of inclusion for individuals with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities 5*, 219–26. https://doi.org/10.1111/j.1741-1130.2008.00183.x

Lincoln, Y.S. and Guba, E.G. (1985). *Naturalistic Inquiry.* Sage Publications.

Keesler, J. M. (2020). Promoting satisfaction and reducing fatigue: Understanding the impact of trauma-informed organizational culture on psychological wellness among Direct Service Providers. *Journal of Applied Research in Intellectual Disabilities*, *33*(5), 939-949.

Kimberlin, S.E. (2009). Political Science Theory and Disability. *Journal of Human Behavior in the Social Environment,19*, 26–43. https://doi.org/10.1080/10911350802619870

Kocman, A., Fischer, L., & Weber, G. (2018). The employers' perspective on barriers and facilitators to employment of people with intellectual disability: A differential mixed-method approach. *Journal of Applied Research in Intellectual Disability*,31, 120–131. doi:10.1111/jar.12375

Krahn, G. L. (2019). A call for better data on prevalence and health surveillance of people with intellectual and developmental disabilities. *Intellectual And Developmental Disabilities*, *57*(5), 357–375. https://doi.org/10.1352/1934-9556-57.5.357

Livermore, G. A., Bardos, M., & Katz, K. (2017). Supplemental security income and social security disability insurance beneficiaries with intellectual disability. *Soc. Sec. Bull.*, *77*, 17.

Macdonald, S. J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J., ... & Dore, S. (2018). 'The invisible enemy': Disability, loneliness and isolation. *Disability & Society*, *33*(7), 1138-1159. https://doi.org/10.1080/09687599.2018.1476224

Mactavish, J., Mahon, M., & Lutfiyya, Z. (2000). "I can speak for myself": Involving individuals with intellectual disabilities as research participants. *Mental Retardation, 38,* 216-227. https://doi.org/10.1352/0047-6765(2000)038%3C0216:ICSFMI%3E2.0.CO;2

Margalit, M. (2004). Loneliness and developmental disabilities: Cognitive and affective processing abilities. *International Review of Research in Mental Retardation, 28,* 225–253. https://doi.org/10.1016/S0074-7750(04)28007-7

McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through unified sports for youth with intellectual disabilities: A five-nation study. *Journal of Intellectual Disability Research*, *57*(10), 923-935. https://doi.org/10.1111/j.1365-2788.2012.01587.x

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

Migliore, A., Mank, D., Grossi, T., & Rogan, P. (2007). Integrated employment or sheltered workshops: Preferences of adults with intellectual disabilities, their families, and staff. *Journal of Vocational Rehabilitation*, 265-19.

Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin*, *55*(3), 176-184.

National Alliance for Direct Support Professionals. (2022). The NADSP competency areas. https://nadsp.org/resources/the-nadsp-competency-areas/

National Core Indicators. (2019). National Core Indicators 2018 staff stability survey report. https://www.nationalcoreindicators.org/resources/staffstability-survey/

Nord, D., & Hepperlen, R. (2016). More job services—Better employment outcomes: Increasing job attainment for people with IDD. *Intellectual and Developmental Disabilities*, *54*(6), 402-411.

Officer, A., & Groce, N.E. (2009). Key concepts in disability. *Lancet, 374*, 1795–1796. http://dx.doi.org/10.1016%2FS0140-6736(09)61527-0

Oliver, M., & Barnes, C. (2010). Disability studies, disabled people and the struggle for inclusion. *British Journal of Sociology of Education*, *31*(5), 547-560.

Ottomanelli, L., & Lind, L. (2009). Review of critical factors related to employment after spinal cord injury: Implications for research and vocational services. *Journal of Spinal Cord Medicine*, 32(5), 503–531.

Overmars-Marx, T., Thomese, F., Verdonschot, M., & Meininger, H. (2014). Advancing social inclusion in the neighbourhood for people with an intellectual disability: An exploration of the literature. *Disability and Society, 29*, 255-274. doi: 10.1080/09687599.2013.800469

Petner-Arrey, J., Howell-Moneta, A., & Lysaght, R. (2016). Facilitating employment opportunities for adults with intellectual and developmental disability through parents and social networks. *Disability and Rehabilitation*, *38*(8), 789-795.

President's Committee for People with Intellectual Disabilities Report to the President. (2017). America's direct support workforce crisis: Effects on people with intellectual disabilities, families, communities and the U.S. economy. https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., … 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

Schalock, R. (2004). The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research, 48*, 203–216. https://doi.org/10.1111/j.1365-2788.2003.00558.x

Sheppard-Jones, K., Prout, H. T., Kleinert, H., & Taylor, S. J. (2005). Quality of life dimensions for adults with developmental disabilities: A comparative study. *Mental Retardation, 43*, 281–291. https://doi.org/10.1352/0047-6765(2005)43[281:QOLDFA]2.0.CO;2

Siperstein, G. N., Parker, R. C., & Drascher, M. (2013). National snapshot of adults with intellectual disabilities in the labor force. *Journal of Vocational Rehabilitation*, *39*(3), 157-165. https://doi.org/10.3233/JVR-130658

Taylor, J. P., Rooney-Kron, M., Whittenburg, H. N., Thoma, C. A., Avellone, L., & Seward, H. (2020). Inclusion of students with intellectual and developmental disabilities and postsecondary outcomes: a systematic literature review. *Inclusion*, *8*(4), 303-319.

Thomson, S. B. (2010). Sample size and grounded theory. *Journal of Administration and Governance*, *5*(1), 45-52. https://ssrn.com/abstract=3037218

Venema, E., Otten, S., & Vlaskamp, C. (2015). The efforts of direct support professionals to facilitate inclusion: The role of psychological determinants and work setting. *Journal of Intellectual Disability Research*, *59*(10), 970-979.

Ward, T., & Stewart, C. (2008). Putting human rights into practice with people with intellectual disability. *Journal of Developmental and Physical Disabilities, 20*, 297–311. https://doi.org/10.1007/s10882-008-9098-4

Ware, N., Hopper, K., Tugenberg, T., Dickey, B., & Fisher, D. (2007). Connectedness and citizenship: Redefining social integration. *Psychiatric Services, 58*, 469-474.

Wehman, P. H., Schall, C. M., McDonough, J., Kregel, J., Brooke, V., Molinelli, A., ... & Thiss, W. (2014). Competitive employment for youth with autism spectrum disorders: Early results from a randomized clinical trial. *Journal of Autism and Developmental Disorders*, *44*(3), 487-500.

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. Journal of Intellectual Disability Research, 45, 371-383. doi:10.1046/j.1365-2788.2001.00342.x

Winsor, J., Timmons, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., & Shepard, J. (2018). Statedata: The national report on employment services and outcomes through 2016. https://scholarworks.umb.edu/thinkwork/47/

World Health Organization. (2011). *World report on disability*. Geneva, Switzerland: Author.

Appendix 1

DSP & Inclusion Semi-Structured Interview Guide

First, I'd like to start by asking a little about yourself.

1. How do you identify your gender?

2. How do you describe your ethnicity/race?

      a. Caucasian/White
      b. African American/Black
      c. Latinx/Hispanic
      d. Asian
      e. Native American
      f. Other (please specify) _____

3. What is your highest level of education?

      a. High School graduate/GED
      b. Some college/ Post high school certificates
      c. Associate's degree
      d. Bachelor's degree
      e. Graduate degree

4. How old are you?

5. Do you have any additional responsibilities or roles outside of being a DSP, such as site manager, team lead, trainer, etc.?

6. What setting/s do you primarily work in as a DSP? (e.g., family home, supported living, group home, etc.)

7. How long have you worked for your current agency/employer?

8. In total how long have you worked as a DSP?

Okay, thank you. Now I will ask you some questions about social inclusion for people with IDD.

1. Before we talk more about social inclusion, I would like to ask how <u>you </u>describe social inclusion?

Thank you for that description. Now, just so we're on the same page, I want to share how social inclusion for people with IDD is typically described in research.

<u>Social inclusion </u>is generally defined as having <u>full and equal access to activities, social roles, and relationships across settings</u> – for example, one's home, community, place of employment, etc. For example, being socially included might look like volunteering in the community with a local non-profit, attending a weekly exercise group, attending church, or having a game night with friends or neighbors.

Is that clear? Any questions? Okay, for the remainder of the interview we will use this definition of inclusion to guide us in thinking about what social inclusion means.

2. How important do you think it is for people with IDD to be included in their community?

3. 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?

4. What barriers or challenges have you encountered when trying to promote social inclusion for people with IDD?

5. How have you worked to overcome each of these barriers/challenges?

6. In what ways does social inclusion impact- positive, negative, or not at all- the lives of people with IDD?

7. 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?

Ok, so we have talked broadly about social inclusion, let's now talk about inclusion in the workforce more specifically.

8. First, what relationship (if any) do you see between social inclusion and employment for people with IDD?

9. Do you believe people with IDD can be employed or have meaningful jobs that they get paid for? If YES**- Okay, what do people with IDD need in order to be successfully employed in the community?**

10. Is it part of your responsibilities as a DSP to help the people you support achieve their employment goals? If YES- **How have you supported individuals with acquiring skills to have a job or to reach their employment goals?**

11. What services does your agency offer to people with IDD to prepare or support them in getting a job? If YES- **What services are offered?**

12. **What do you see as barriers to getting someone with IDD a job? And what are strategies for overcoming these?**

13. What are your thoughts on the role of sheltered workshops in helping people with IDD reach their employment goals? *(A sheltered workshop is a private non-profit, state, or local government institution that provides employment opportunities for people with IDD, to prepare them for gainful work in the general economy. These programs are typically found in segregated spaces, are meant to be temporary, and offer participants sub-minimum wages*).

14. To what extent do Individual Support Plans or ISP (sometimes referred to as Person-Centered Individualized Support Plans or PCISPs) inform how you provide support to people with IDD?

15. This question is related to benefits. Are you aware if the people you support receive any state or federal benefits/assistance and if so, what type/s?

16. Okay, final question**- Is there anything else you would like to share or add about social or workforce inclusion for people with IDD?**

Table 1 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)
Additional Role/ Responsibilities	
Yes [a]	5 (23.8)
No	16 (76.2)
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. ($N = 21$). [a] Day Aid, Community Liaison, Site Supervisor, Team Lead, & Trainer

Table 2 Four Emerging Categories and their Respective Codes

How do DSPs' describe their role and responsibilities in promoting social and workforce inclusion for people with IDD?	
Category (1)	*Balancing role responsibilities and individual preferences*
Codes	Inclusion as normative and vital to well-being
	Respecting choice and individualizing support needs
Category (2)	*DSPs as gatekeepers to inclusion*
Codes	Opening doors to new experiences and opportunities
	Skills training to promote inclusion
What challenges exist in promoting social and workforce inclusion for people with IDD and how can these be overcome?	
Category (3)	*Systemic barriers to inclusion*
Codes	Disability disempowerment
	Inaccessible communities
	Exclusion by services
	Lack of meaningful agency training and support
How can disability providers better support inclusion?	
Category (4)	*Creating opportunities to advance inclusion*
Codes	Valuing DSPs' expertise and involvement
	From programs to a way of life