Intellectual and Developmental Disabilities

An equity-based research agenda to promote social inclusion and belonging for people with IDD

--Manuscript Draft--

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Abstract:	Having a sense of social inclusion and belonging, typically characterized by our personal relationships and community participation, is the central essence of life for most people, yet it remains elusive for many people with intellectual and developmental disabilities (IDD). This article summarizes work of a diverse group of researchers and advocates to propose six big-picture equity-oriented goals to drive future research in the field: (1) understanding the role of intersectionality, (2) understanding intimate relationships, (3) promoting formation of communities of care to support social inclusion, (4) understanding life course trajectories of social inclusion, (5) understanding social inclusion in virtual spaces, and (6) understanding how to promote social inclusion in the entire research process.

Thank you very much for your review of our manuscript "An equity-based research agenda to promote social inclusion and belonging for people with IDD". We appreciate the reviewer's thoughtful comments, and have responded to each in text and in the grid below.

Reviewer Comment	Authors' Reply	Location & Nature of Edit
1) Methodology recommendations should also mention the need for universal design in research. Eg., easy read informed consent to participate, teachback methodology, the use of vignettes or other technique to enhance comprehension of research questions, trauma-informed research approaches to help reduce the likelihood of harm from asking research questions that require people with disabilities to reflect on traumatic experiences, accessible dissemination of research findings to empower and inform study participants, etc. Even better, people with disabilities would co-produce the research questions/methods. This needs to be built into the design of the research, as opposed to ad hoc corrections/adaptations after.	Thank you for the suggestions. We touched on many aspects of research inclusion in the section on "Inclusion in the Research Process" and have added the reviewer's suggestions to bolster that section.	1st paragraph of the "Inclusion in the Research Process", added, "In future research, it is our recommendation that people with IDD move firmly into co-researcher roles, and that universal design principles are incorporated into research design. Such applications may include (but not be limited to) easy to comprehend informed consent documents, use of trauma-informed research approaches that will avoid retraumatizing people with IDD in the research process, and using accessible dissemination strategies (video, easy-to-read documents, social media posts, etc.) to empower people with disabilities to use research findings to improve their lives and engage in advocacy."
2) Any conversation of social inclusion and belonging as it pertains to people with IDD feels incomplete if it doesn't include discussion about attitudes towards disability. At a minimum, this paper should include some summation of literature on attitudes towards individuals with disabilities. For example, this global research study on attitudes towards IDD that demonstrated that the	We have added a brief "Note on community attitudes" on p. 6.	See paragraph under the new heading "Note on Community Attitudes" on p. 6.

general population endorses the rights of people with IDD at high levels, their ability to carry out the activities that they have a right to do (e.g., education, jobs) at a lower level, and their intention to include people with IDD at the lowest levels: Slater, P., McConkey, R., Smith, A., DuBois, L.A. & Shellard, A. (2020) Public Attitudes to the Rights and Community Inclusion of People with Intellectual Disabilities: A Transnational Study. Research in Developmental Disabilities. doi: 10.1016/j.ridd.2020.103754 There are many other examples of attitudes research that could be included in a high-level summary.		
3) I appreciate how this article mentions lifecourse trajectories as it pertains to social inclusion and belonging. I agree that this is an area that warrants further research, but I think it may be worth mentioning in the paper that there are certain aspects of community engagement/participation for which there has been a significant amount of research. For example, there is a lot of research on employment for people with IDD, including how employment outcomes and experiences differ from people without IDD. Not all of this research includes the perspectives of employed people with IDD, but it can be a potential starting point for	We are hesitant to add a section on employment for two reasons: (1) employment was a separate strand in the SoS meeting, and we do not wish to tread on the territory of our colleagues, and (2) many conceptualizations of SI&B, including Simplican's, which was the basis for our own conceptualization used in this paper, do not attend directly to employment, as it is seen as a rather distinct life doman… in most conceptualizations, SI&B is really about personal relationships and social participation in its essence, and employment is fairly different from those intents. Thus, we have chosen not to act on this recommendation, aside from adding a line to	Last sentence under "Definitions and Theoretical Orientation" we added, "Please note that for our purposes, we are placing some boundaries upon social inclusion, so that we will be discussing social participation and relationships, but not specifically other domains such as residential settings or employment, which, while related to social inclusion, fall outside the scope of many of the leading conceptualizations.""

building on the lifecourse trajectories, and this paper would be remiss to not make a more explicit mention of what is known about some of these more well-studied areas.	indicate the bounds of what we are considering in our discussion of SI&B.	

An equity-based research agenda to promote social inclusion and belonging for people with IDD

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Abstract

Having a sense of social inclusion and belonging, typically characterized by our personal relationships and community participation, is the central essence of life for most people, yet it remains elusive for many people with intellectual and developmental disabilities (IDD). This article summarizes work of a diverse group of researchers and advocates to propose six big-picture equity-based goals to drive future research in the field: (1) understanding the role of intersectionality, (2) understanding intimate relationships, (3) promoting formation of communities of care to support social inclusion, (4) understanding life course trajectories of social inclusion, (5) understanding social inclusion in virtual spaces, and (6) understanding how to promote social inclusion in the entire research process.

Key Words: social inclusion, belonging, friendships, community participation, intellectual and developmental disabilities

An equity-based research agenda to promote social inclusion and belonging for people with intellectual and developmental disabilities

For most of us, having a sense of belonging is an essential part of our life experience. Whether we are at home, at work, at school, or at play, we want to feel as if we have a place in the world. This sense of belonging is the essence of social inclusion, and it has too often remained elusive for people with intellectual and developmental disabilities (IDD), even as we have made progress toward more inclusive living, learning, and working options. This article outlines our current state of understanding about social inclusion and belonging (SI&B), and it posits critical questions for the IDD field to consider to improve our understanding of social inclusion and belonging in the next 10 years, with particular emphasis on how we can better meet the needs of people with IDD who hold multiple marginalized social identities.

What Do We Know About Social Inclusion and Belonging?

Definitions & Theoretical Orientation

Central to the conceptualization of social inclusion and belonging is the notion that ‘‘social inclusion’’ goes beyond mere physical inclusion to encompass relationships, membership, community participation, and belonging (Bogenschutz et al., 2015). Thus, social inclusion involves a range of relationships, including friendship and intimate relationships, and full community participation, not just having a presence or being there (Bogenschutz & Amado, 2016; Hall, 2009). To account for and address this complexity in research and practice, Simplican and colleagues (2015) proposed an ecological model of social inclusion for people with IDD, defined as the interaction between interpersonal relationships and community participation. Subsequently, Simplican (2019) built on the original model by suggesting that social inclusion is an “essentially contested” concept in that it is influenced by social and political values and by context. Rather than trying to force social inclusion and belonging into a precise definition, flexibility and open-endedness are necessary for researchers who want to understand the complexity of the concept (Simplican, 2019). Using such a framework allows us to explicitly consider the impact of ecological conditions at the individual, interpersonal, organizational, community, and socio-political levels that may promote or hinder social inclusion for people with IDD, particularly those with multiple marginalized social identities (Simplican, 2019; Simplican et al., 2015). Please note that for our purposes, we are placing some boundaries upon scope, so that we will be discussing social participation and relationships, but not specifically other domains such as residential settings or employment, which, while related to social inclusion, fall outside the scope of many of the leading conceptualizations.

Community Participation

While physical presence in the community does not necessarily indicate full integration, community participation remains an important aspect of social inclusion and belonging (Amado et al., 2013; Louw et al., 2020). Simplican and colleagues (2015) posited that community participation for a person with IDD can be considered according to the type of activities in which they engage, the structure of the settings in which the activities take place, and their level of involvement with others in the activity. Community participation may include leisure activities (e.g., hobbies, arts, sports), political or civic activities, productive activities (e.g., employment, education), religious and cultural activities, and consumption activities (i.e., access to goods and services). These activities may take place in segregated, semi-segregated (i.e., include only people with IDD and paid staff, but take place in community settings), or integrated settings. While engaging in these activities, people with IDD may have different levels of community involvement ranging from presence (i.e., physical inclusion with little to no contact with others) to encounter (i.e., interactions with strangers in the community) to participation (i.e., community involvement that promotes development of interpersonal relationships). People with IDD may have different levels of involvement depending on the activity or context, and they may progress to more meaningful involvement over time. Since encounters are a key aspect of social inclusion, it is important to understand how people with IDD experience those encounters and the contexts that affect their inclusion (Bigby & Wiesel, 2011). For example, young adults with IDD and pervasive support needs whose parents described being satisfied with their community participation shared that the young adults' consistent presence in the community led to increased encounters with others over time and the development of relationships as they got to know each other through shared time and experiences (Rossetti et al., 2015).

Community participation should reflect and contribute to meaningful daily lives for people with IDD. Parents and caregivers of people with IDD have emphasized the importance of reciprocity and fit with one's environment (e.g., community activities, individualized supports, social interactions) and broader, more nuanced goals rather than traditional post-school outcomes of employment, post-secondary education, and independent living (Henninger & Taylor, 2014). Relatedly, time spent meaningfully by people with IDD has been described as being active in the community, independent of one's parents/caregivers, with similarly-aged peers (with or without disabilities) or staff, and engaged in interest-based or purposeful activities that make one happy and/or have a positive impact on others (Rossetti et al., 2015). Community participation also includes having social roles that are valued by the person with IDD and members of their community. As Hall (2016) found, people with IDD were able to take on leadership roles in the community by participating on committees, teaching skills to peers, leading volunteer activities, and advocating for people with IDD.

Interpersonal Relationships

Using the ecological model of social inclusion (Simplican et al., 2015), interpersonal relationships for a person with IDD can be examined according to the people in one's social network and their relationship to the person with IDD, the structure of individual relationships and social networks, and the kinds of social support received. Interpersonal relationships may include relationships with family members, friends, acquaintances, paid staff, and intimate partners. As with the general population, extant research indicates that friendships and intimate relationships support wellbeing for people with IDD (Eisenman et al., 2017; Friedman & Rizzolo, 2018). Friedman and Rizzolo (2018) found that having quality friendships, as defined by the person with IDD, was significantly associated with higher quality of life for people with IDD. Notably, having friendships was also associated with participation in the community. This supports Simplican's (2015) ecological model of social inclusion as an interaction of interpersonal relationships and community participation. The structural components of relationships and social networks include elements like how people met, how long they have known each other, how frequently they spend time together, who initiates the time together, where they spend time together (e.g., home, community, online), and the types of social support needed and provided in the relationship.

Because individuals with IDD tend to interact primarily with family, paid staff, and other people with IDD (Bogenschutz et al., 2015), it is important to purposefully and proactively consider supports and social opportunities in the community that may lead to authentic friendships and intimate relationships. Friendships are relationships that involve mutuality, shared interests, companionship, intimacy, and reciprocity (Rossetti & Keenan, 2018). One way to think about authenticity is that friendships should be "horizontal" relationships characterized by equality and reciprocity, which are qualitatively different from "vertical" relationships characterized by differences in social capital, power, or status and that may be unilateral in terms of caring or support (Bagwell & Schmidt, 2011). Holding high expectations and believing that people with IDD can and should have authentic friendships and intimate relationships is a critical first step. Individuals with IDD may need support (e.g., facilitated social opportunities, education about different types of relationships) to develop and maintain safe and healthy relationships. With appropriate support, they should be able to exert control and choice regarding friendship, intimate relationships, and sexuality or gender expression (Hughes, 2022; Rushbrooke et al., 2014).

Despite efforts to improve social inclusion, we know that loneliness and social isolation continue to be commonplace for people with IDD (Emerson et al., 2021; Petroutsou et al., 2018). The COVID-19 pandemic intensified social isolation and feelings of loneliness and stress for people with IDD, highlighting the importance of social support and relationships (Fisher et al., 2022). Gilmore and Cuskelly (2014) identified three reciprocally influencing components of vulnerability to loneliness for people with intellectual disabilities: social environment (e.g., negative attitudes, low expectations), social experiences (e.g., reduced social opportunities, limited social interactions), and personal characteristics (e.g., social skills, self-regulation). Notably, this framework highlights the importance of intervention at the environmental level instead of just at the individual level, emphasizing the critical nature of social inclusion and belonging for people with IDD, their families, and society as a whole.

Note on Community Attitudes

The attitudes of community members are bound to affect S(&B for people with IDD. Though a full review of the literature on the topic of community attitudes is beyond our scope, it bears mentioning that recent literature has found wide general support for the inclusion of people with IDD in the social fabric of societies around the world (McConkey et al., 2021; Slater et al. 2020), though community members express markedly less facility in carrying on activities that would promote social inclusion (Slater et al. 2020). Internationally, McConkey (2019) found that the Irish public tended to be more open to social inclusion of people with physical or sensory disabilities than to people with intellectual disabilities. Similar findings were reported by McConkey and colleagues (2021) in a U.S.-based study.

What We Can Learn From Other Fields: Inclusion Case Study

The desire for social inclusion cuts across contexts and social groups, and the IDD field can learn much from how social inclusion and belonging have been promoted in other contexts. There are many organizations doing excellent work to promote social inclusion and belonging. As an example, we can consider how 4-H Extension Educators have worked to create a culture of inclusion for LGBTQ+ youth within the Minnesota 4-H program.

Rural LGBTQ+ youth have fewer support resources than their urban peers (Kosciw et al., 2009). While rural youth have experienced discrimination in schools, their communities, and religious organizations, 4-H youth development programs are uniquely positioned to provide supportive spaces and programs for these youth, having grown out of the same communities (Rand & Paceley, 2021).

Many of the supports that have helped 4-H programs promote better social inclusion for LGBTQ+ youth are structural. For instance, many 4-H programs are housed within land grant universities across the U.S. that have non-discrimination policies that support work with marginalized groups. While research indicates LGBTQ+ young people have been a part of the 4-H program in the U.S. for many years (Howard et al., 2021), the National 4-H Council stated its commitment to parity within the next decade, specifically calling out sexual orientation and gender identity non-conforming youth in its work to ensure the 4-H membership reflects the diversity of the populations and communities in which it serves (United States Department of Agriculture, 2017). A national 4-H LGBTQ+ committee created a tool to support the inclusion of people of all sexual orientations and gender identities in youth development programs that addresses traditionally gendered programming, dress codes, discriminatory policies and practices, and communication strategies (Program Leaders Working Group, 2020). While many local and state 4-H groups have begun to adopt or embed these practices, there remains work to be done to equip staff and volunteers with tools to support transgender youth (Gonzalez et al., 2021).

A study of the 4-H program in Minnesota reiterated the need for staff training on LGBTQ+ practices, discriminatory policies, practice change, and specific programming for and about LGBTQ+ youth that is co-created with LGBTQ+ youth to amplify their voices (Rand et al., 2021). Addressing this need, Minnesota 4-H staff at all levels of the organization have engaged in LGBTQ+ inclusion training multiple times in the last few years. Policies that create barriers for young people, like dress codes and language, have been reviewed and revised. Staff have also intentionally engaged LGBTQ+ youth in educational opportunities and program development.

The structural approaches to improving inclusion of LGBTQ+ youth in 4-H may serve as a model for service providers and state agencies wishing to promote better social inclusion and belonging of people with IDD who hold multiple marginalized social identities. The strategies displayed by 4-H may be duplicated and adapted within the disability context to inform future research strategies as well.

Overview of Goal Development Process

In September 2022, a diverse array of established researchers, emerging scholars, self-advocates, and family members convened at the State of the Science in IDD virtual conference. Much of the work of that conference was done in topically-oriented strands, including a strand on social inclusion and belonging, which drove this work.

Over two days, the strand engaged in semi-structured discussions to explore what we know, what we need to know, how we can generate and disseminate applied knowledge, and the pressing questions that need to be addressed to help us move forward toward better social inclusion and belonging for people with IDD. The research goals presented below are the end product of our meetings.

Throughout our time together, we sought to bring particular focus onto the needs and perspectives of people with IDD who hold multiple marginalized social identities, with the intent of developing research goals that will ultimately be more inclusive and culturally relevant than social inclusion and belonging research to date. The goals presented in this article aim to improve on past oversights that have led to our limited understanding about how to promote social inclusion within the context of multiple marginalized social identities, by firmly framing the centrality of social identity and intersectionality in our future research.

Note on Language

Members of this workgroup chose to use the language *multiple marginalized social identities* in this article, and a note on this language choice is warranted. *Multiple* refers to the fact that all people hold a number of different identities, which may be more or less salient in a particular context and which shape a person's interaction with the world and the world's interaction with a person. While having IDD is the central social identity at the heart of this paper, additional identities are important and shape each person's experience differently. *Marginalized* refers to the idea that society has an ingrained power structure that privileges some identities (typically the dominant identity) and devalues others (typically minority identities). The devaluing of minoritized identities often places people who hold those identities at society's margins. *Social identities* refers to the fact that any identity is socially constructed, fluid, and subject to change depending on contexts of time, place, and social milieu. Identity is not a fixed attribute that neatly fits into categories. Our language choice is meant to convey inclusion of identities broadly, and not confined to any particular prescribed set of socially-defined categorizations. Thus, our language choice is meant to convey an acknowledgement that identity matters far beyond the surface level, and includes deeply embedded cultural norms that can affect a person's opportunities to pursue social inclusion and to feel a sense of belonging in relationships and community spaces. It is against this backdrop of power and oppression, both historical and current, that we offer the remainder of our work.

What Do We Need To Know?

Members of the 2022 State of the Science Social Inclusion and Belonging Strand spent much time talking about what we need to know in order to support greater social inclusion and belonging. The three topics covered in this section synthesize much, though not all, of our discussion.

How to Make SI&B Relevant in Cultural Contexts

First, our strand members were in agreement that social inclusion and belonging research in the IDD field has underrepresented and excluded racial and ethnic diversity.

Individuals with racialized, intersectional, and multiple marginalized social identities have been systemically and systematically excluded from SI&B research. Having such scant research to represent the experiences of individuals from multiply marginalized social groups poses many limitations, including limited applicability of research findings. Notably, research conducted with predominantly White samples is used under the assumption that findings may apply across cultures, even though it may not actually translate across social identities.

Moving forward, the SI&B strand members call for more attention to structural and social contexts that shape how people with IDD who hold multiple marginalized social identities (1) seek and attain social inclusion, (2) experience settings that are meant to be socially inclusive, and (3) shape how people with IDD and their families make decisions about how, when, where, and with whom social inclusion and belonging is sought. Illustrations may help to clarify the importance of understanding SI&B in cultural context. For instance, ample prior research has demonstrated the potential utility of faith communities in fostering social inclusion for people with IDD (Amado et al., 2013). The interventions that contributed to much of the work in this area were largely conducted in White Christian congregations, and findings generally followed the logic of those congregations. In contrast, Shikarpurya and Singh's (2021) study of South Asian Muslims in mosques in the U.S. provided a more nuanced cultural context. Their research suggested that newer immigrant families may have more difficulty finding a sense of belonging for their family members with IDD than families with a longer experience in the U.S., and that culturally-based stigma around disability may also play a role in how South Asian Muslims with IDD in the U.S. seek social inclusion.

While these perspectives may also be present in other racially and/or ethnically minoritized communities, we know very little about opportunities to foster and cultivate social inclusion for those communities within faith-based contexts. In order to move our knowledge of SI&B forward, IDD researchers must first partner with people from multiply marginalized communities to conceptualize, design, and lead studies that redefine SI&B for specific subgroups of marginalized communities. Definitions, experiences, and expectations of SI&B must be contextualized for each multiply marginalized community to center and reshape their experiences with SI&B within IDD research.

SI&B in a Changing Social Environment

Since the last State of the Science meeting in 2015, the American social environment has shifted dramatically. The COVID-19 pandemic, which had disparate impacts on both people with IDD (see Gleason et al., 2021; Landes et al., 2021; Turk et al., 2020) and on communities of color (see Mackey et al., 2021; Mude et al., 2021; Romano et al., 2021) has changed the sensibilities of many Americans about socialization and group gatherings. The renewed racial justice movement has raised public consciousness that racism matters in determining social participation, LGBTQ+ Americans have seen their social identities challenged through public discourse and policy, and our society is relying on technology more than ever to develop and maintain relationships and to form community (Hacker et al., 2020). People with IDD have not been immune from any of these social trends, yet IDD research on SI&B repeatedly continues to default to traditional notions of what constitutes relationships and community participation, and issues of intersectionality are often omitted from consideration in our research.

In order to understand SI&B in our current social context, we must adapt as IDD researchers and understand that the world has changed. We need to better understand how people with IDD are faring in the context of these new social realities, design interventions for creating IDD-inclusive communities of care, and develop promising practices to help people with IDD navigate and interact in new social contexts safely and fully. In the midst of these challenges lie opportunities for creating a new notion of what SI&B can look like for people with IDD when researchers find ways to meet the challenges of conducting research in new social contexts.

Revisiting Theory & Methods

As researchers work toward greater understanding of SI&B, particularly for people with IDD who hold multiple marginalized social identities, it will be necessary to more deeply evaluate the methods that we use to conduct our research, since methods ultimately hold the power to either reproduce exclusionary practices of the past or help us work toward more complete and inclusive understandings.

More specifically, we suggest researchers apply frameworks (e.g., Disability Critical Race Theory, intersectionality) and methodologies (e.g., critical qualitative inquiry, critical participatory action research) that contextualize factors that sustain and reproduce disparate outcomes related to SI&B as well as connect and amplify multiply marginalized voices (Crenshaw, 1991; Delgado & Stefancic, 2017; Johnson et al., 2021).

For example, Disability Critical Race Theory (DisCrit) provides an intersectional analysis of racism and ableism - how they are co-constructed and sustained through discourses, social norms and practices, and institutions that limit access and participation in daily life for people with disabilities from minoritized social identities (Annamma et al., 2013).

Intersectional methodologies such as Critical Participatory Action Research (cPAR) create the conditions for research partners from multiply marginalized social identities to name, frame, and transform contextual factors that cause harm as well as to develop forms of emancipatory action that meet their needs through collaborative learning and planning (Kemmis et al., 2004). Further, cPAR provides a conceptual framework that aligns research partners with issues experienced by people who hold multiple marginalized social identities, changes power relations in terms of who possesses the knowledge to enact change, and empowers collaborative action between research partners and others to develop targeted, culturally and socially relevant strategies.

The use of quantitative methods aimed at understanding structural factors that contribute to social determinants of social inclusion has also been evolving. Intersectionality and the unequal distribution of social power have been key drivers of examining the currently used quantitative methods and their sensitivity to studying the predictor, mediator/moderator, and outcome variables of people with multiple marginalized social identities. Because this type of inquiry is quite new, there are currently no comprehensive guidelines for selecting the most appropriate quantitative methods to reflect intersectionality, structural factors, and power differences in society that are relevant to specific communities. Two systematic reviews (Bauer er al., 2021; Guan et al., 2021) have not only identified promising analytic approaches addressing different identities and structural inequalities (e.g., regression trees, chi-square automatic detection analysis, intersectional mediation analysis, etc.), but also other concerns related to setting up data analysis. These include implementing models limited to the study of main effects without accounting for meaningful interactions and a lack of justification for the selection of a statistical method and covariates. In the social sciences, and specifically in studying SI&B of people with IDD, we need to be more intentional in how we analyze and interpret data to assure that we are representing people's identities, and the meanings of those identities within social context, rather than just a collection of their demographic information. Similarly, we need to ensure that we are selecting analytical methods that more accurately portray existing imbalances of power and structural inequities among individuals and communities of different backgrounds and prioritizing different values in our research designs and analytic approaches.

Research Priorities

Understanding Intersectionality

Our first research priority seeks to understand how (and to what extent) intersectionality plays a role in social inclusion for people with IDD who also identify with other marginalized social identities. Since there is scant existing SI&B research in the IDD field that centers on the experiences of people with multiple marginalized social identities, it is necessary to start with a basic grounding in how intersectionality influences SI&B. Intersectionality provides a framework for dissecting human experiences from historical, sociopolitical, and relational lenses (Collins &

Blige, 2016; Crenshaw, 1991). The core foci of intersectionality include (a) social context, (b) power, (c) social inequality, (d) complexity, (e) relationality, and (f) social justice (Collins & Blige, 2016; Rice et al., 2019). In relation to SI&B, intersectionality inspires IDD researchers to untangle how power, oppression, and privilege coordinate and transact through all social groups (Johnson et al., 2021; Rice et al., 2019). In other words, it helps scholars to better understand how constructions of disability, socialization, and belonging are interconnected and informed by multiple marginalized identities (e.g., disability, race, ethnicity, age, sexuality, etc.; Collins & Blige; Crenshaw, 1991; Few-Demo et al., 2022).

Existing IDD research does not adequately account for intersectionality when examining SI&B. Though there are many questions to pursue to help us understand intersectionality, exploring how the social position of a person with IDD and their family affects choices to pursue community activities and relationships and to what extent their social decisions are influenced by intersectionality is foundational to understanding SI&B for people with IDD and additional marginalized social identities.

Understanding Intimate Relationships

There is ample evidence to suggest that people with IDD have desires for love and sex that are similar to people without disabilities (Arias, 2009; Morales et al., 2014). We also know that there are ways to help people with IDD build skills for understanding healthy relationships and how to avoid relationships that may be dangerous for their wellbeing (Dinora et al., 2021). Yet we continue to see that people with IDD have fewer intimate relationships than most members of our communities, and that opportunities to form intimate relationships may be particularly challenging when a person with IDD identifies with a minoritized sexual orientation or gender identity (Abbott & Howarth, 2007). For that reason, our second research aim seeks to better understand intimate relationships.

In order to build intimate relationships, people with IDD need opportunities to talk about their desires for intimacy, to learn about healthy sexual relationships, to date, and to form families. Often, intimacy and sex have been taboo topics for people with IDD, which have sometimes even been blocked by policy (Onstot, 2019), and protectionist attitudes have often prevailed from caregivers and service providers. In order to promote opportunities for intimate relationships, researchers may want to consider scaling training programs designed to help people with IDD understand healthy intimacy, work with service providers and family networks to normalize intimacy and sexuality, and design and test interventions that can support people with IDD in the dating scene. Understanding and designing systems to support parenting with a disability are also important to the goal of supporting intimate relationships. Finally, we should note that sexuality is a part of the lives of people with IDD, regardless of whether they engage in sexual activity (Bathje et al., 2021).

People with IDD who identify with a marginalized sexual orientation or gender identity/expression may require particular support to pursue intimate relationships. The development of supportive spaces for the expression of gender identity and sexual orientation that intersect with IDD is essential, as the expression of one's gender identity and sexual orientation are a part of one's expression of self determination (Hughes, 2022). Additionally, supportive relationships with family and professional caregivers that honor expressions of gender and sexuality as a normal part of self-determination are essential.

Communities of Care

Communities of Care are designed to support wellbeing and mental health by building social connections, improving access to community opportunities, and ensuring equitable access to resources (Stebleton, 2019). Since we know from prior research (Esler et al., 2019; Scott & Havercamp, 2014) that mental health conditions are far more prevalent in people with IDD than in the general population, and that histories of personal and community-level trauma likely contribute to mental health challenges for people who are racially minoritized (Goldman et al., 2021) and members of the LGBTQ+ community (Sattler & Zeyen, 2021), it is likely that people with IDD who hold multiple marginalized social identities may face particular mental health and wellbeing challenges. Intentionally fostering social inclusion through the development of Communities of Care may serve as a protective factor that supports not only SI&B, but also overall wellbeing.

Communities of Care to support SI&B of people with IDD may be established anywhere: schools, service providers, community organizations, faith communities, and so forth. In the past, IDD researchers have successfully worked with faith communities (Amado et al., 2013) in order to establish Communities of Care to help build inclusion for people with IDD. Schools have often worked to build Communities of Care to support the mental health of students, with particular attention to students with marginalized social identities, to mitigate the effects of minority stress. Recognizing the particular mental health challenges that are likely to come at the intersection of IDD and other marginalized social identities, the proactive establishment of Communities of Care could be a way to build SI&B into mainstream IDD services, and, importantly, to support people with IDD within predominantly minority-serving structures (e.g., predominantly Black or Latinx-serving faith communities), ethnically-defined social groups (e.g., a Korean-American society), or clubs formed around a particular sexual orientation or gender identity.

Building culturally-relevant and disability-friendly Communities of Care is a complex endeavor that will take committed partnerships, trust, and dedication. Researchers who wish to help establish such Communities of Care would be advised to invest in relationships first, and may consider participatory methods for conducting research alongside members of the community, especially if they are attempting to build Communities of Care within organizations or communities in which they do not share membership. Through long-term commitments, Communities of Care may be established and sustained, and hold the potential to support both SI&B not only for people with IDD, but also for broader communities.

Life Course Trajectories of SI&B

Understanding life course trajectories has been a priority for researchers and practitioners in many areas of IDD research, including health and behavioral health (Gorter et al., 2014) and family caregiving (Reynolds & Palmer, 2019). Though there have been no empirical studies that we are aware of to track trajectories of SI&B over time, we feel it may be particularly useful to understand how experiences early in life may predict later experiences of SI&B in the lives of people with IDD. Particularly since we know that loneliness among people with IDD has been reported across the lifespan (Petroutsou et al., 2018), and that loneliness can have an adverse affect on health outcomes in the general population (Park et al., 2020), it is important that we begin to gain a better understanding of how to influence positive social inclusion outcomes for people with IDD early in life in order to set the stage for long-term SI&B.

Conducting longitudinal studies can be difficult, expensive, and impractical, so it may be difficult to conduct research on SI&B trajectories over the lifecourse using longitudinal designs. Particularly since many population-based datasets that collect consistent data over time do not collect adequate data to identify people with IDD, secondary analyses may also be challenging. These challenges pose obstacles to understanding life course trajectories of SI&B without a long term investment of time and resources. To address some of these challenges, retrospective studies that qualitatively ask people with IDD and/or their supporters to think back to early experiences may be useful to construct patterns of SI&B over time. It also may be possible to use large, representative datasets that include relationship and community participation variables to construct models of social inclusion among participants of different ages and in different living conditions. Methods such as propensity score matching may have particular utility in such examinations, as this method can artificially construct equivalent samples based on a shared set of characteristics, enabling meaningful comparisons across groups. We also acknowledge that discrimination may play a major part in the SI&B trajectories for people with IDD who hold multiple marginalized identities, so it is important that our research designs intentionally account for the potential roles of social marginalization and structural discrimination in a meaningful way.

SI&B in Virtual Spaces

The way in which Americans build and maintain relationships is shifting, with virtual social communities and online relationships now coexisting alongside social opportunities “in real life.” People with IDD also seek social inclusion via social media, and there are indications that online relationship quality for people with IDD is comparable to that of people without IDD, and that people with IDD who use social media report an increase in friendships (White & Forrester-Jones, 2020). Further, there is some evidence that social media can be a welcoming social environment for people with IDD, who have reported that the stigma associated with disability is less prevalent in online communities (Sweet et al., 2020). Social media has also been noted by people with IDD as a place where they may freely express themselves and experience autonomy, leading to a sense of competence and connectedness (Chadwick & Fullwood, 2018), though cyberbullying remains a challenge in some contexts (McHugh & Howard, 2017). Considering the increasing presence of social media in how we all interact and engage in communities that interest each of us, we believe it is essential to understand how people with IDD can and do use virtual spaces to build SI&B.

While there are many interesting research lines to pursue relating to SI&B in virtual spaces for people with IDD, we believe understanding the SI&B experiences of people with IDD and multiple marginalized social identities is particularly important since virtually nothing is written about SI&B in virtual spaces from an intersectional perspective. For instance, we would be interested to explore whether experiences of discrimination that occur in real life are duplicated in online spaces, especially in online communities organized around shared interests (e.g., hobbies, education), or whether virtual communities may be more accepting of people with IDD, especially when they have multiple marginalized social identities. With such base knowledge, we may be able to inform interventions and policies aimed at promoting full participation, and better prepare people with IDD for successful online social interactions.

We are also quite interested in how identity-based affinity groups may help people with IDD who hold multiple marginalized social identities find a sense of belonging. As Chadwick and Fullwood (2018) noted, social media communities can be powerful venues for people with IDD to network and share information. Since social opportunities and challenges are often contextualized by one's social identities, virtual communities that form around particular identities may be especially powerful to help people with IDD find a place of belonging and navigate social inclusion in the broader community. For instance, communities of Black women with IDD may have particular power to help navigate racialized misogyny in the workplace, just as a group for transgender people with autism may provide a place of comfort and belonging that is difficult to establish in the real world, thereby providing an important protective factor for a group that is at high risk for mental health challenges and suicidal behavior. As researchers, understanding the power of such groups is important, as they may play a critical role in the lives of people with IDD who hold multiple marginalized social identities, not only in terms of SI&B, but also in terms of overall wellness and safety.

Inclusion in the Research Process

People with IDD have a fundamental right to be involved in decision-making processes that affect their lives, including decisions about research, and the benefits gained from their participation (Bigby et al., 2014; Schwartz et al., 2020). Inclusive research aligns participatory and emancipatory approaches with people who have IDD. In inclusive research: (1) the unit of study or investigation is owned (not necessarily initiated) by people with IDD; (2) it furthers the interests of people with IDD, with academicians/researchers supporting those interests; (3) it is collaborative; (4) it enables people with IDD to wield control over process and outcomes; and (5) it develops products that are accessible (Walmsley & Johnson, 2003; Schwartz et al., 2020). Bigby and colleagues (2014) described inclusive research as a spectrum where traditional research, led by academic researchers, is on the far left and emancipatory research, where people with IDD make major decisions, is on the far right. Inclusive research is commonly practiced in the middle where people with IDD may serve as advisors, have leadership roles, or work in partnership with research teams. In future research, it is our recommendation that people with IDD move firmly into co-researcher roles, and that universal design principles are incorporated into research design. Such applications may include (but not be limited to) easy to comprehend informed consent documents, use of trauma-informed research approaches that will avoid retraumatizing people with IDD in the research process, and using accessible dissemination strategies (video, easy-to-read documents, social media posts, etc.) to empower people with disabilities to use research findings to improve their lives and engage in advocacy.

Further, inclusive research often takes a political stance and must bring about change for individual research partners (i.e., people with IDD), the wider group of which they are members, and the social institutions and process that continue to oppress people with disabilities (Bigby & Frawley, 2014), which has direct implications for people with multiple marginalized social identities. Critical considerations for inclusive research processes must also include forming genuine, longstanding, and mutually beneficial relationships with minoritized communities, as well as building in supports for their engagement in research.

As applied to SI&B research, this may mean that academic researchers take the time necessary to build authentic and mutually beneficial relationships with organizations that typically support people with IDD and multiple marginalized social identities, and listen carefully to their preferences about if, how, and when to engage in research that is meaningful to them. It also involves selection of co-researchers who are prepared to be active participants and not simply representatives, dedication of time and resources to build relationships and support participation, and work on the part of academic researchers to understand their own social positions and how to navigate the SI&B research space alongside people with IDD who hold multiple marginalized social identities.

Conclusion

Our relationships and our opportunities and choices about how to engage in our communities are central to our lived experience, and research in the IDD field has often not pursued SI&B research as fully as we have pursued other topics. By looking at extant literature as well as gaps in that literature, this paper sought to illuminate potentially fruitful research pathways to improve SI&B outcomes for people with IDD. Further, we have proposed ways in which researchers may center the experience of people with IDD who hold multiple marginalized social identities, with the aim of producing more equitable outcomes and a more nuanced understanding of the SI&B experiences of multiply marginalized people within the IDD community.

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