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Diverse perspectives on supporting the health and wellness of people with intellectual and developmental disabilities

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ABSTRACT

Background: Persons with intellectual and/or developmental disabilities (IDD) are a growing population, frequently living with complex health conditions and unmet healthcare needs. Traditional clinical practice and research methods and measures may require adaptation to reflect their preferences.
Objective: The perspectives of people with IDD, caregivers/partners, and clinicians were obtained to provide insight into factors contributing to the health and wellness of people with IDD. These, in turn, suggest opportunities for improvements in clinical training and care, and considerations for enhancing research methods and measures.
Methods: An exploratory design, participatory methods, abductive qualitative approach and thematic analysis were employed. Interview data were obtained in twelve focus groups with people with IDD ($n = 25$), caregivers/partners ($n = 21$), and clinicians ($n = 27$). Particular attention was paid to supporting attendees in focus group participation, with adaptations and accommodations made for communication preferences, and graphic illustrations were provided.
Results: Themes emerging across attendee categories that reflect factors contributing to health and wellness for people with IDD include: (1) making healthy choices; (2) participating in everyday activities; (3) benefitting from natural supports (e.g., family, friends, peers); and (4) accessing skilled professional supports (e.g., healthcare provision and payment).
Conclusions: Study findings underscore factors related to supporting health and wellness for people with IDD and suggest the importance of autonomy, accessibility, healthy relationships, self-advocacy, and tailored clinical care. People with IDD can be actively engaged throughout the research enterprise to ensure the relevance, acceptability, and accessibility of research methods and measures; promote inclusiveness; and address health disparities.

1. Introduction

Individuals living with disabilities are a health disparities population, often unrecognized and underserved, and extremely vulnerable to poor outcomes.[1–5] Persons with intellectual and/or developmental disabilities (IDD) are a growing population in the U.S.,[6] numbering at least 10 million people, who are frequently living with complex, co-occurring physical or mental health conditions and unmet healthcare needs.[7–16] While attention to this population has been encouraged,[17,18] the field struggles with a lack of data regarding prevalence and intervention effectiveness,[8,19,20] inadequate or inappropriate research methods or outcome measures,[21–23] and insufficient engagement of people with IDD in research.[18]

The involvement of people with IDD is essential to understanding the dynamic, complex nature of health and related outcomes in this heterogeneous population.[24] Investigators, including those with IDD, have

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developed guidelines for adapting traditional research approaches to mitigate assumptions about (in)competence to consent, the over-reliance on parents or caregivers as proxy respondents, and barriers to participation conveyed by inaccessibility, poor design, or irrelevance.[23,23,25,26] Recommendations include implementing diverse methods (e.g., online surveys, focus groups), considering cognitive accessibility and communication preferences, and embracing universal design in developing or adapting materials (e.g., self-reported health and quality-of-life measures).[21,23]

To address health disparities, enhance wellness, and inform healthcare as well as research, the logical next step is to engage individuals in describing facilitators and challenges in achieving their desired health and wellness outcomes.[27] Social-ecological or "person-context" models provide an approach for understanding people with IDD within their relationships, community, society, and service systems.[28,29] Given that improvements in outcomes will derive from interactions with and within these networks, the perspectives of others in their lives (e.g., caregivers/partners, clinicians) are also important to understand.

This study is embedded in the larger, two-wave Individuals with IDD Engaged, Aligned, and Leading project (IIDDEAL), in which people with IDD contributed as community experts and partners in all stages of implementation.[16] The project's overall goals are to actively engage people with IDD, caregivers/partners (e.g., family members, personal care assistants), clinicians (e.g., physicians, nurses, dentists), and payers/regulators in identifying and prioritizing health outcomes and making recommendations for improving and measuring those outcomes. During 2022 and 2023, over 180 individuals participated in semi-structured individual and group discussions and consensus meetings.[16]

This paper provides findings from second wave data collection via focus groups, designed to maximize input from diverse community experts as befitting a socio-ecological perspective, while elaborating prioritized outcomes and recommendations for achieving them. We address the research question, "What contributes to the health and wellness of people with IDD, from the diverse perspectives of people with IDD, caregivers/partners, and clinicians?" Findings provide insight into opportunities for enhanced clinical care and inform the adaptation of research methods and measures.

2. Methods

In wave 1 of the project, we explored health outcomes as prioritized by attendees in project activities. An exploratory design, participatory methods,[16] abductive approach,[30] and thematic analysis of qualitative data were employed in this second wave of the project to draw conclusions from focus group discussions regarding contributors to health and wellness for people with IDD. Wave 1 themes provided the foundation for wave 2 inquiry and elaboration.[31] Team members collaborated with the original project team and advisors to develop, refine, and implement procedures for the second wave.[32] The Brandeis University Human Research Protection Program reviewed and determined that the project did not meet the federal definition of human subjects research.

2.1. Wave 1 provided the foundation

The first wave of data collection with community experts, conducted in Spring 2022, provided the foundation for second-wave data collection between November 2022 and May 2023. Attendees in wave 1 identified nine prioritized health outcome domains: making healthy choices; emotional or mental health; physical health, reducing pain, and increasing energy; sexuality, gender, reproductive health, and parenting; being able to do the things I love or need to do; family caregiver/partner wellness and support; clinical workforce development; system supports; and payer/regulator priorities. These domains were the foundation for further exploration in the second wave. Wave 1 protocols provided the foundation for wave 2 procedures; wave 1 findings informed the initial coding framework for wave 2 analyses. This is consistent with an abductive approach, in which our extant understanding (i.e., informed by wave 1 themes) is further elaborated in a recursive and iterative process. Wave 2 data are used to elaborate our understanding of the phenomenon under study (i.e., contributors to health and wellness) from multiple perspectives (i.e., reflecting the "layers" or levels of the social-ecological model).[30]

2.2. Recruitment in wave 2

Potential attendees for second-wave focus groups were identified through purposive and snowball sampling via networks across the U.S. known to project personnel. Recruitment flyers were created for people with IDD, caregivers/partners, and clinicians, and disseminated through advocacy and professional organizations. Flyers specified that attendees could be individuals with IDD age 18 and older (including their support persons if desired), caregivers/partners of people with IDD, and clinicians serving the IDD population. Given the exploratory nature of the work, there were no explicit exclusion criteria. Potential attendees completed an online registration form with questions regarding gender, pronouns, race, geographic location, disability and/or relationship with people with IDD, support needs, availability, communication preferences, and profession.

People with IDD were contacted by a team member (an experienced female service provider and community engagement consultant) for an individual orientation session (e.g., 15- to 30-min telephone or video call) to confirm their willingness and ability to participate, and to identify any supports needed to optimize participation. In advance of the focus groups, people with IDD received an email reminding them of the session, a copy of the slides to be used, and a link to a 5-min, closed captioned video prepared by the facilitator/researcher, introducing herself and her interest in the topic, providing project background, and describing what to expect in the group session. Caregivers/partners and clinicians were invited to participate and emailed further information about participation. All attendees were offered a choice of focus group, day and time, and supported throughout the project using email, telephone, informational videos, illustrated guides, plain-language materials, and video conferencing. Attendees were volunteers; all those who agreed to attend did so, except for a few with last-minute schedule conflicts that precluded attendance.

2.3. Procedures

Twelve focus groups were conducted in wave 2, four with each category of attendees (i.e., people with IDD, caregivers/partners, and clinicians). Meetings were held for 60–90 min on Zoom® with closed captioning, facilitated by senior team members (i.e., experienced female, doctoral-level clinicians/researchers with positions in academic or national non-profit organizational settings) with professional and personal experience with people with IDD. The communication preferences of all attendees were respected, including spoken language, assistive and augmentative communication (AAC) devices, and/or text in the chat function, at times with the help of a family member or personal care assistant. Attendees were encouraged to take their time to share and to respect others' contributions.

Following introductions, the facilitator reviewed slides with graphic illustrations of health outcomes generated in prior wave 1 sessions to prompt discussion of health, wellness, and healthcare experiences. Using Miro® whiteboard software, with procedures carefully explained and supported, attendees reflected on previous themes and added new ideas about health outcomes for group consideration. Additional focus group prompts included questions about what was needed to manage and achieve these health outcomes. Attendees contributed from multiple perspectives. For example, many clinicians had both professional and personal experience with people with IDD (e.g., a family member with IDD). Notetakers (i.e., female, trained, master's-prepared individuals/

advanced undergraduate research fellow) captured people's comments, perceptions, and recommendations verbatim, as well as comments contributed through the chat or AAC devices. The team reviewed notes between sessions to inform preparation for subsequent focus groups. Sessions were audio-recorded with permission and Zoom® transcripts generated.

2.4. Analysis

Registration data were analysed quantitatively and summarized to describe attendees. Focus group data, including detailed notes, session recordings and transcripts, and graphic illustrations, were systematically read, discussed, and reviewed by project team members as they became available. Transcripts were uploaded into Dedoose® software for management and analysis.[33] Initial codes reflected wave 1 outcome domains. All transcripts were coded independently by four team members, who met routinely to develop a shared understanding of new codes and emergent themes, and to reach agreement on additional ideas, patterns, relationships, and nuance offered by wave 2 attendees. Cronbach's alphas achieved at least .90, suggesting excellent inter-coder agreement.[34] Summary analytic memos regarding themes and relationships were prepared and discussed by the team, providing a mechanism for sharing, exploring, and challenging assumptions and interpretations regarding patterns in the data.[35] Trustworthiness was established via the iterative data collection process, triangulation of attendees' multiple perspectives, systematic review of coding, discussion of memos, and ongoing review of findings by the larger IIDDEAL team and advisors with professional and lived experience.[32]

3. Results

3.1. Attendees

A total of 73 individuals attended one of the twelve focus groups. (See Table 1.) Findings were attributed to attendees as defined by the session they chose. Of the 25 people attending the IDD focus groups, most were between 31 and 50 years (60 %) and identified as female (72 %). They were primarily White and non-Hispanic (68 %); fewer were Black (8 %) or Asian (4 %). Twelve percent were parents. People with IDD were geographically diverse, from the Northeast (24 %), South (36 %), Midwest (32 %), and Western U.S. (8 %). The majority preferred verbal communication with chat and closed captioning as options (64 %). A few participated using ACC devices (8 %). The vast majority (88 %) were Medicaid and/or Medicare beneficiaries.

Caregivers/partners (n = 21) were largely parents (76 %) of individuals with IDD; some were siblings, friends, or professional care assistants (5 % respectively). Fourteen percent identified as living with IDD themselves. Nearly half (48 %) supported one person, while one-third (33 %) supported two people, and 14 % supported three or more. The majority of persons supported were age 18 or older (62 %).

The 27 clinician attendees were actively licensed (100 %), seeing patients (81 %), and prescribing medication (74 %). They included physicians, physician assistants, dentists, nurses, psychiatrists, mental health professionals, and an audiologist. Half of those currently seeing patients indicated that less than 25 % of their caseload included patients with IDD, though 45 % indicated that people with IDD of all ages comprised more than 76 % of their caseloads. One clinician identified as a person with IDD.

Table 1
Background and demographic characteristics.

	Individuals with IDD (n = 25)	Caregivers/ Partners (n = 21)	Clinicians (n = 27)
	n (%)	n (%)	n (%)
Age			
18–30	6 (24 %)	1 (5 %)	2 (7 %)
31–50	15 (60 %)	7 (33 %)	13 (48 %)
51+	4 (16 %)	13 (62 %)	12 (44 %)
Gender			
Female	18 (72 %)	20 (95 %)	21 (78 %)
Male	6 (6 %)	1 (5 %)	6 (22 %)
Nonbinary	1 (4 %)	0 (0 %)	0 (0 %)
Race/Ethnicity			
White, non-Hispanic	17 (68 %)	16 (76 %)	19 (70 %)
Black, non-Hispanic	2 (8 %)	3 (14 %)	1 (4 %)
Asian, non-Hispanic	1 (4 %)	1 (5 %)	2 (7 %)
Multiracial or other race, non-Hispanic	1 (4 %)	0 (0 %)	2 (4 %)
Hispanic	2 (8 %)	1 (5 %)	1 (4 %)
Prefer not to say	2 (8 %)	0 (0 %)	2 (7 %)
Region of US			
Northeast	6 (24 %)	9 (43 %)	11 (41 %)
South	9 (36 %)	3 (14 %)	7 (26 %)
Midwest	8 (32 %)	4 (19 %)	5 (19 %)
West	2 (8 %)	5 (24 %)	4 (15 %)
Preferred Mode of Communication			
Verbal only	5 (20 %)	8 (38 %)	11 (41 %)
Verbal with chat, closed captioning, and/or live scribe	16 (64 %)	13 (62 %)	14 (52 %)
Other (Chat only, AAC device, etc.)	4 (15 %)	0 (0 %)	2 (7 %)

3.2. Contributing to health and wellness

Four themes described the factors contributing to overall health and wellness as suggested by group attendees: (1) making healthy choices; (2) participating in everyday activities; (3) benefitting from natural supports (e.g., family, friends, peers); and (4) accessing skilled professional supports (e.g., healthcare provision and payment). These themes are somewhat interrelated, as highlighted in attendees' quotes.

3.3. Making healthy choices

People with IDD and caregivers/partners noted that *healthy choices are unique to individuals* as they relate to self-management and self-care, seeking healthcare and advice from professionals, and self-advocacy. Both groups suggested that health, wellness, and feeling positive about oneself in general involve prioritizing wellness and taking time for self-care. People with IDD underscored the importance of "doing the things I should be doing, like getting enough sleep" and "taking care of my teeth." What may be healthy for one person may not be healthy or safe for another. For example, people with IDD explained that, rather than focusing on watching one's weight, "… eating a diet that is healthy …" may be a better goal. The same distinction was made between exercise and movement. While traditional exercise may not be possible for a person with a physical disability, focusing on healthy, safe movement "that feels good for our bodies" may be more appropriate. Having access to environments that support healthy choices (e.g., local parks, walking trails) is key, according to people with IDD and caregivers/partners.

People with IDD agreed that *knowing one's body* is important to self-management and self-care efforts. The continuum of "listening to my body" experiences ranged from people with IDD expressing that they knew when they weren't well (e.g., "We all know how we feel when we're tired or you haven't slept well …") to experiences where people expressed challenges with understanding their body's cues. This continuum of knowing one's body impacts self-management and healthcare, as reflected by caregivers/partners: "… it's not just knowing when their body is experiencing pain … but their ability to express that to people …" such as healthcare professionals.

People with IDD, caregivers/partners, and clinicians agreed on the importance of *self-advocacy and collaboration* with clinicians to inform decisions and make healthy choices. Factors outside of a person's control and, therefore, beyond their advocacy efforts (e.g., limited community resources, few options for housing or transportation), may undermine

their ability to make healthy choices, access healthcare, and achieve wellness goals. A caregiver/partner emphasized the role of individual agency and autonomy; building the capacity to be heard and ask for help in whatever mode is effective; and being able to say "no" to treatment or procedures a person doesn't understand. Informed decision-making included the importance of being able to make informed choices about intimacy; consent and being able to consent to intimate interactions or experiences; and safety in both in-person and online relationships.

3.4. Participating in everyday activities

Being able to do everyday things was important to people with IDD, and echoed by caregivers/partners and clinicians. These include activities like watching television, playing music, walking in nature, having a pet, or participating in sports. Being part of a faith community was mentioned by some people with IDD. Attendees underscored the value of leisure activities and social connection, doing "… things that help me feel connected to other people that give me a sense of community" (a person with IDD). These activities provide opportunities to identify and capitalize on strengths: "I loved being in the drama club … that kind of opened up the door to people that didn't have IDD" (a person with IDD). Getting to choose what to do and where to go is empowering. A routine schedule and realistic, tiered goals were perceived as promoting day-to-day success.

Having a sense of purpose or meaningful activity also contributes to health and wellness. "Patients with IDD want … things that give life meaning and purpose …" (a clinician). Employment, mentorship, volunteering, or political activism can convey a sense of purpose, as can being part of an organization: "… meaning and connection come up as things that I love and need to do, and that contribute to my overall wellness …" (a person with IDD). Positive role models in activities and organizations may provide examples of successful community engagement and goal achievement.

Accessibility underlies the ability of people with IDD to enjoy everyday activities. Accessible housing provides the foundation for pursuing interests independently; transportation is essential to going places. A person with IDD who enjoys travel described many challenging situations (e.g., inaccessible hotels or restaurants). Overcoming these accessibility barriers requires environmental or contextual change, rather than "fixing" the person with IDD. "We need to get away from the idea of … 'if we keep training you, you'll be independent, because that is what's breaking people …" (a caregiver/partner).

3.5. Benefitting from natural supports

Attendees across groups discussed the importance of *family, friends, partners, and peers*. Caregivers/partners discussed the role of "trusted advisors" and relationships that help people with IDD make healthy choices. Clinicians described the importance of collaborating with families. While people with IDD noted they often rely on their families, many explained that this is not always convenient. They do not want to feel like a burden or their family resources are limited. "Some of us just don't [have large families for support]. It's my mom and eventually [she's] not going to be there …" (a person with IDD). Other people with IDD talked about not feeling safe or supported by their families. They described relying on the deep friendships they develop with others: "So, it could be an online disability group … I consider them my family …" People with IDD underscored the importance of having a supportive partner who understands and respects their needs. "Having a healthy relationship … makes ourselves feel better" (a person with IDD).

People with IDD noted that *social support* often starts in virtual or in-person groups with people with shared experiences or interests. Virtual meetings allow for flexibility in location and mode of participation (e.g., video, closed captioning). In-person meetings may be available at independent living centers or special needs programs. Although group meetings were noted as a helpful way for people with IDD to meet others, attendees also noted that friendships should extend beyond disability. A person with IDD explained the importance of developing deeper friendships, encouraging people to support one another through all aspects of life: "… you should be able to talk beyond simply peer support, because you can have peers who you might not have much in common with other than your shared disability." People with IDD also mentioned that the type of support they rely on changes over time: "Some people with disabilities are at completely different points in their lives …". Younger people may need more support from others with IDD, but as people get older, they may rely on deeper friendships and support for reasons other than coping with disability. People with IDD with histories of trauma spoke about the benefits of peer support in coping with experiences like sexual assault.

3.6. Accessing skilled professional supports

Attendees across all groups had a great deal to say about healthcare and other professional supports, insurance, and payment. Attendees acknowledged that mental and physical health are interconnected and that treatment must focus on the "whole person." They agreed that *knowledgeable clinicians with positive attitudes,* who are respectful and sensitive to individual identities, preferences and needs, are hard to find. "Healthcare providers are barriers to accessing good healthcare and services for people with IDD because of their attitudes or because they don't know certain things" (a clinician). People with IDD and clinicians stressed the importance of clinicians understanding "… your patient's culture and access to different language interpretation services … beyond using plain language … having someone who is culturally humble." Clinicians emphasized tailoring healthcare to individuals' needs, such as those related to age.

Attendees recommended *modifications to patient care routines*. Several clinicians indicated that telehealth visits are helpful for some people with IDD. Some clinicians adjusted visit time limits, a move supported by people with IDD and caregivers/partners. A person with IDD explained, "… oftentimes it takes us months to get these appointments, and then … you maybe get 15 min with a provider, and they rush you through everything …" Some clinicians made efforts to "help folks with IDD get procedures" because "we know folks with IDD are less likely to get screenings."

Finding *therapists skilled in working with people with IDD* was identified as essential for those with mental health challenges. "I wish there were more therapists that understood patients with IDD" (a person with IDD). Trust and feeling safe in treatment relationships are important, especially for those who have been traumatized in the past, as emphasized by people with IDD, caregivers/partners, and clinicians alike. People with IDD noted that mental health treatment should involve a range of accessible modes, including non-traditional options. Many people with IDD and caregivers/partners expressed concerns about inappropriate or ineffective use of psychiatric medications. "There needs to be a conscious effort to make sure that medication isn't being used just to make people easier to handle" (a caregiver/partner).

Perhaps most importantly, people with IDD, caregivers/partners, and clinicians agreed on the importance of *neuro-affirming and identity-sensitive counseling*. It is about "accepting the person for who they are" rather than trying to "normalize" the person. People with IDD felt more comfortable talking with providers who focus on intersectional elements of identity in care visits. They explained that clinicians need more training on caring for people with IDD, especially regarding sexual and reproductive healthcare. One clinician emphasized, "Patients with IDD want what everyone else has … We need to talk about contraception, consent, healthy relationships."

The importance of *advocacy in the healthcare system*, being able to advocate for yourself or with the support of others, was emphasized by people with IDD and caregivers/partners. "… if you have a disability … if you're not a cisgender, heterosexual man … doctors will not listen to you as well as they listen to someone who might be in a more privileged

position …" (a person with IDD). Tension may arise when clinicians are attentive to others in the room, rather than the person with IDD. "One of the doctors that I used to go to … he didn't focus on me and talk to me. He talked to my mom" (a person with IDD). Caregivers/partners described circumstances in which they struggle to shift the attention away from themselves and elevate the needs and preferences of their family member; "There is a difference in caregiving when you are serving as somebody's local proxy and communicating their needs, but still trying to do it from the orientation of that individual's needs." Diagnosing and responding to pain and prescribing appropriate pain management medications were described by caregivers/partners as challenging for clinicians.

All attendees highlighted the potential benefits of *care coordination, collaboration, and teamwork* among providers, so they can "understand how their roles and their resources can come together and work together in ways that support our community" (a person with IDD). Clinicians emphasized the importance of communication among different types of providers, as well as payer relationships that promote access to coordinated services for people with IDD. "We need a workforce that is trained to work together" (a clinician).

Challenges with *adequate insurance coverage* were described by many. "It depends on what your insurance accepts. If you don't push for certain things, they're not going to necessarily be offered to you" (a person with IDD). Insurance does not necessarily cover the services people with IDD want (e.g., nutrition, chiropractic, dental care). Navigating payment systems can be confusing. As one person with IDD explained, "The choices we can make are limited by the choices that are available to us, and the choices … are often determined by structural factors or things outside our control. I think it's just really important to explicitly talk about funding, to talk about access, and to talk about equity."

4. Discussion

Diverse focus group attendees provided ample evidence of the convergence of perspectives on themes related to health and wellness for people with IDD: (1) making healthy choices; (2) participating in everyday activities; (3) benefitting from natural supports; and (4) accessing skilled professional supports. The interrelationships among themes and across levels of analysis (e.g., individual, family and community, healthcare system) underscore the benefits of framing people's experiences in a social-ecological model. The nuance in discussions, and the description of unique interests, preferences, and needs highlight the importance of autonomy, accessibility, healthy relationships, and tailored, person-centered care, with individualized goal-setting and achievement measures.

Our findings provide further nuance to an understanding of health disparities among people with IDD and strategies for addressing them. For example, investigators have highlighted high rates of health risks and chronic health conditions for these individuals, while bringing attention to underlying physical inactivity and inadequate social or emotional support.[1–3] These challenges, and solutions to these challenges, cross thematic domains in this study and levels of analysis suggested by the social-ecological model. For example, physical activity may be related to a person's understanding of their own body and the importance of self-care, the notion of a sense of purpose (e.g., a destination or reason for taking a walk), feeling connected and wanting to walk with a friend or family member, and the accessibility of outdoor spaces or transportation in the community. These interrelated themes and the activities they reflect may be supported by professionals who encourage participation in everyday activities, or undermined by those who minimize or overlook the capacity of a person with IDD to pursue these goals. People with IDD must be engaged as partners, along with caregivers/partners, and clinicians, in the contexts in which they live and work, to achieve health and wellness goals and improve outcomes.

Challenges faced by people with IDD, caregivers/partners, and clinicians suggest the potential benefits of enhanced clinical training, practice change, and healthcare systems transformation (e.g., payment models, quality metrics). Our findings confirm, enhance, and strengthen those of prior studies, underscoring the need to overcome barriers and address gaps in services for people with IDD.[15,36–39]

Our experience conducting this study has further implications for addressing research challenges and the lack of relevant methods and measures.[19,23,27,29,40] Research procedures must support multiple, accessible modes of engagement and implementation (e.g., visual, auditory, written). Individuals have specific preferences related to language (e.g., "exercise" versus "healthy movement"), that will greatly impact metrics and measures designed to capture health and wellness. When individuals and assessment developers do not have a shared understanding of terms, measurement validity may be compromised.[41,42] Family involvement, routinely considered in service planning and social support measures, may not be positive or available. Outcome measures must be considered in light of individualized goals, strengths, and capabilities, as well as community and systems availability and accessibility. Many of these research challenges can be addressed by engaging individuals with IDD and other community experts throughout the research process. As our experiences in this study suggest, people with IDD are, at best, treated as partners in developing a shared understanding of relevant research questions and prioritizing outcomes; implementing methods and procedures that encourage and support active participation throughout the research process; and interpreting findings, placing them in the larger social-ecological context, for wide dissemination and use.

5. Limitations

Our findings are limited by the sample to some extent. Data on the prevalence of individuals diagnosed with IDD most often focus on children; these data suggest the higher prevalence of Black, non-Hispanic and male in those diagnosed.[43] The current study sample of adults includes higher percentages of White, non-Hispanic and female attendees with IDD. Given the purposive, snowball sampling approach, attendees in all categories likely represent individuals with commitments to improving the lives of people with IDD, suggesting potential bias.

6. Conclusion

Focus groups of people with IDD, caregivers/partners, and clinicians underscore the unique, shared, and challenging aspects of achieving health and wellness for people with IDD. Themes include: (1) making healthy choices; (2) participating in everyday activities; (3) benefitting from natural supports; and (4) accessing skilled professional supports. Findings suggest the importance of autonomy, accessibility, healthy relationships, self-advocacy, and tailored, personalized clinical care. Gaps in research and healthcare must be addressed, centering the experiences of people with IDD and the contexts in which they attempt to achieve their desired health and wellness goals. People with IDD must be actively engaged to ensure the relevance, acceptability, and accessibility of clinical care and research, promote inclusiveness, and address health disparities.

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Previous presentations

None to report.

Ethical review

The project was reviewed by the Brandeis University Human Research Protection Program which determined that this work does not meet the federal definitions of Human Subjects Research. Therefore, the project did not fall under the jurisdiction of the Institutional Review Board.

CRediT authorship contribution statement

Joanne Nicholson: Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Kristen Faughnan:** Writing – review & editing, Writing – original draft, Project administration, Investigation, Formal analysis, Data curation. **Allie F. Silverman:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. **Victoria Lesser:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. **May-Lynn Andresen:** Writing – review & editing, Supervision, Resources, Project administration, Investigation, Funding acquisition, Conceptualization. **Madelyn Bahr:** Writing – review & editing, Resources, Project administration, Investigation. **Tim Corey:** Visualization, Data curation, Conceptualization. **Teal W. Benevides:** Writing – review & editing, Supervision, Resources, Project administration, Investigation, Funding acquisition, Conceptualization. **Hoangmai Pham:** Writing – review & editing, Supervision, Resources, Project administration, Investigation, Funding acquisition, Conceptualization.

Declaration of competing interests

The authors declare they have no competing or conflicts of interest.

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