

Inclusive Methods for **Engaging People With Intellectual and Developmental Disabilities** in Research Practices

Tonie Sadler, PhD



What Does Research Engagement With People With IDD Look Like?

People with intellectual and developmental disabilities (IDD) have the right to engage in research that affects their lives and to contribute meaningfully to the processes and outcomes of disability research. According to the U.S. Health and Human Services (HHS) Administration for Community Living’s 2022 *I/DD Counts* summit report (2023), data on the health and well-being of people with IDD are critically lacking, due in part to the exclusion of people with IDD in the research process. As a result, “it is more difficult to identify issues that may uniquely or disproportionately affect people with [IDD]” (HHS, 2023, para 7). In addition to expanding inclusion in traditional research settings, research in virtual environments—which increased substantially after the COVID-19 pandemic—offers more opportunities for geographically diverse and marginalized groups to participate, thus creating space for new voices and perspectives in disability research.

This info brief describes the historical context in which people with IDD have been excluded from research practices, discusses considerations for the COVID-19 pandemic and research participation, presents an overview of research methods for engaging people

with IDD in research, and includes a list of resources for including people with disabilities in research practices.

A History of Exclusion

People with IDD, especially those with the greatest needs for support, continue to be excluded from research practices. Those from historically underserved groups (e.g., Black; Indigenous; Hispanic; lesbian, gay, bisexual, transgender, queer, intersex, and asexual/ aromantic/agender plus [LGBTQIA+]; older adults) have been systemically excluded from research due to social and economic factors such as economic instability, limited education opportunities, underserved neighborhoods and environments, and limited or no access to health care (Asare et al., 2017). Further, many members of these communities historically have been excluded from research due to systemic bias in eligibility for study participation and sample designs that failed to accurately identify underserved groups and their needs (Gehlert & Mozersky, 2018; Kissel & Friedman, 2023). Without the participation of people with IDD, including those from underserved communities, research findings related to a broad range of topics—health, health care, employment, education, independent living—may not be relevant or actionable for those most affected by the research (Bard, 2021; DeCormier Plosky et al., 2022; Feldman et al., 2014; Jacobson et al., 2013; Spong & Bianchi, 2018).

Approximately 75% of clinical trials funded by the National Institutes of Health have directly or indirectly excluded adults with intellectual disabilities, and just over 33% of the studies have used “direct exclusion criteria based on cognitive impairment or diagnosis of intellectual disability” (McDonald et al., 2022). Other exclusion factors include level of cognitive capacity, functional capacity, and ability to read and write. Similarly, a survey found that the research designs of more than 90% of clinical trials excluded children with developmental disabilities, even though they could have been included in approximately 70% of the studies had reasonable accommodations been provided during the consent process and study execution (Feldman et al., 2014).

Reasons for excluding people with IDD include concerns about the individual’s ability to consent, risk of exploitation or harm, vulnerability or frailty, and negative impact on study

results (DeCormier Plosky et al., 2022; Feldman et al., 2014; McDonald et al., 2022). These assumptions are misguided and without empirical support. Further, when people with IDD do participate in research, researchers may inadvertently create barriers to valid, reliable, and meaningful data about their experiences and outcomes, such as inaccessible study materials, lack of research participation supports, and data collected from a proxy rather than from the individuals themselves (McDonald & Raymaker, 2013; McDonald et al., 2022a).

COVID-19 and Research Engagement in Virtual Environments

The shift to conducting research in virtual environments after the COVID-19 pandemic presented new challenges and opportunities for ensuring accessibility and inclusion of people with cognitive disabilities in the research process. In response to these challenges, many researchers turned to remote data collection methods, such as telephone and online surveys, short message service (SMS; i.e., text messages), videoconferencing, and self-collection of data. Although it is too early to know the full effects of conducting research remotely, both positive and negative consequences are apparent. For example, conducting research online or by telephone/SMS may remove barriers associated with transportation, commute time, recruitment, and participant time commitment (Keen et al., 2022; Roberts et al., 2021). However, challenges of conducting research in virtual environments include lack of access to technology, difficulty building rapport with participants, technological hurdles, and data security threats (Hensen et al., 2021; Loucks et al., 2021).

These concerns likely are amplified for people with IDD because of extraneous cognitive load and processing challenges, inability to see or interact with visual cues or communication aids, and inability to engage physically with study materials and research guides. Conversely, research in virtual environments has the potential to offer accessibility resources that facilitate research participation that may not be possible in traditional, in-person settings, such as allowing participants to have more control in the research environment, individualized accessibility study adaptations, and use of video or other media in virtual settings (Miller & van Heumen, 2021).

Research Methods Used for Engaging People With IDD: A Call for Inclusion and Accessibility in Research

In response to these challenges, researchers have engaged in methods to promote inclusive research practices—i.e., advisory, leading, and collaborative models of engagement (Bigby et al., 2014). Methods include but are not limited to **(a) adapting research materials and processes into individualized and accessible formats** (Kenny et al., 2023; McDonald et al., 2016; McDonald et al., 2022a; McDonald et al., 2022b; Nicolaidis et al., 2011, 2020; Raymaker et al., 2017, 2019; Rios et al., 2016; Williams & Moore, 2011), **(b) adopting inclusive research participation methods** (Bumble & Carter, 2020, 2021; Jurkowski, 2008; Overmars-Marx et al., 2018; Povee et al., 2014; Williamson et al., 2020), and **(c) community participation and co-researcher engagement** (Bigby et al., 2014; Di Lorito et al., 2018; Nicolaidis et al., 2011, 2019, 2020; St. John et al., 2018). The following sections outline common approaches to engaging people with IDD in research, including models and frameworks used to implement the methods.

ADAPTING RESEARCH MATERIALS AND PROCESSES INTO INDIVIDUALIZED AND ACCESSIBLE FORMATS

To advance inclusive research practices, some researchers have increased the accessibility of research materials to improve meaningful participation among individuals with IDD who have different support needs. In their accessible research design approach, Rios et al. (2016) described a three-tiered model for promoting accessibility of research for people with disabilities. The model includes (a) universal design, (b) accommodations, and (c) modifications. In Universal Design of Research, Williams and Moore (2011) promoted the “design of research so that all people can be included as potential participants, to the greatest extent possible, without the need for adaptation or specialized design” (p. 3). Strategies in universal design include using large, dark print; making websites and other resources compatible with screen readers; and using plain language in consent forms and other written materials. While universal design provides a baseline of accessibility in research design, accommodations and modifications may be necessary “to enable equal participation” throughout the research process (Rios et al., 2016, p. 2139).

Nicolaidis et al. (2020) outlined common challenges in adapting existing survey instruments for use with some adults with autism and people with IDD. These challenges include the use of difficult vocabulary, imprecise response options, and ableist language or concepts. The authors recommend a collaborative process for addressing these issues to improve accessibility and inclusiveness when developing and implementing survey instruments. They identified five common adaptation strategies: (a) adding prefaces to increase precision or explain context; (b) modifying items to simplify sentence structure; (c) substituting difficult vocabulary words, confusing terms, or figures of speech with more straightforward terms; (d) adding hot links that define problematic terms or offer examples or clarification; and (e) adding graphics to increase clarity of response options (p. 62).

Similarly, McDonald et al. (2022a) proposed a multiphase process to facilitate the inclusion of people with IDD in the design and administration of a self-report survey. They identified five key strategies: (a) building trust, (b) showing respect, (c) designing accessibility into the survey, (d) maximizing flexibility, and (e) allowing individualized accommodations. Throughout the research process, they used qualitative inquiry and community engagement to “learn from and with historically marginalized groups” (p. 177).

ADOPTION OF METHODS FOR INCLUSIVE RESEARCH PARTICIPATION

In addition to adapting existing research materials into accessible formats, researchers have adopted inclusive research methods such as photovoice, World Cafés, and technological interventions to increase research participation among people with IDD. Developed by Wang and Burris (1994), photovoice enables research participants to “take photographs which are later used to facilitate reflection on their feelings, ideas and experiences” (Overmars-Marx et al., 2018, p. 92). Photovoice is a community participatory method that has been used primarily with research participants from underserved communities, including individuals with IDD. It affords participants the opportunity to reflect on their lives and gives them a voice to advocate for change in their living environment (Jurkowski, 2008; Overmars-Marx et al., 2018; Povee et al., 2014). Overmars-Marx et al. (2018) provide a standardized approach, called *guided photovoice*, to applying photovoice in research involving people with IDD. This approach entails a multistage process of preparation, taking photographs, and conducting interviews and post-interviews. Researchers are present to assist and support the process as necessary or desired.

The World Café is another community participatory approach used in research to engage the disability community, including people with IDD. World Cafés, which typically last from 2 hours to a full day, engage diverse community members in “solutions focused” dialogue about public-facing issues (Bumble & Carter, 2020, p. 1). Originally, the World Café was not designed as a research method (Brown & Isaacs, 2005); however, disability researchers increasingly use this model to “examine issues affecting the lives of people with disabilities” (Bumble & Carter, 2020, p. 2). In a review of the World Café as a methodology in disability issues, Bumble & Carter (2020) introduced a framework for assessing researchers’ use of World Cafés. The framework includes 26 distinct quality indicators organized in seven categories: (a) clarity and rationale, (b) participants and setting, (c) procedures, (d) data collection, (e) data analysis, (f) mixed-methods studies, and (g) participatory studies (Bumble & Carter, 2020, p. 130).

With respect to technological interventions to enhance inclusion of people with IDD in research, the COVID-19 pandemic prompted a shift to conducting research in virtual environments. This shift presented new challenges and opportunities for ensuring accessibility and inclusion of people with IDD. In a review of technology use among research teams collaborating with people with IDD, Hwang et al. (2021) found that researchers used technological interventions to improve team formation and function, data collection, data analysis, and dissemination. To facilitate these processes, technological tools included photo-sharing software, slide presentations, online surveys, data analysis software, videos, online discussion platforms, audio recorders, web videoconferencing, email, and telephone communication. Technological accommodations that were made to ensure people with IDD could access technologies included the use of tablets, stylus tools, screen reader-compatible materials, camera equipment, and text-chat software.

COMMUNITY PARTICIPATION AND CO-RESEARCHER ENGAGEMENT

The term *inclusive research*, coined by Walmsley (2001), refers to research that involves people with disabilities beyond their participation as “subjects” or “respondents.” Involvement in inclusive research encompasses a range of participatory roles, from membership on an advisory board or council to the role of a co-researcher or “people lead,” in which individuals with IDD or representative organizations lead and control research processes (Bigby et al., 2014).

Most commonly, methods of inclusive research involve participation in an advisory board or council made up of organization representatives, family members, and individuals with IDD who share input on research activities. While feedback from the IDD community is critical for inclusive research, researchers have criticized the limitations of these methods, pointing out a lack of “real power-sharing” (Di Lorito et al., 2018, p. 670).

In response, researchers have moved toward methods that place people with IDD and their community advocates in leadership and power-sharing roles throughout the research process. For example, in co-research approaches, “people with intellectual disability collaborate with academics to investigate the experience of their own peers” (Di Lorito et al., 2018, p. 670). From their research partnerships with autistic adults, Nicolaidis et al. (2019) developed seven guidelines to foster the inclusion of autistic adults as co-researchers. These guidelines include (a) provide transparency about partnership goals, (b) define community partner roles, (c) create processes for effective communication and power sharing, (d) focus regularly on building and maintaining trust, (e) collaboratively disseminate findings, (f) actively encourage community capacitation, and (g) fairly compensate community partners for their work (p. 22).

Conclusion and Resources to Support Research Teams

Although progress has been made and inclusion strategies have been employed, as outlined in this brief, minimal guidance is available on the continuous processes necessary to engage people with IDD rigorously in research, including methods that have been tested for validity and reliability. Further, research that examines how these methods have been tested in virtual environments is limited. Given the systematic exclusion of people with IDD in research and the lack of studies that examine effective and reliable methods in traditional and virtual environments, it is crucial to address identified gaps to ensure that people with IDD are meaningfully engaged in research processes to improve assessment and measurement of the needs of the IDD community.

Resources

The following list presents a selection of resources for engaging people with disabilities in research practices.

- [AASPIRE Inclusive Research Toolkit](#) — The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) developed an inclusive research toolkit that aims to “create equitable, effective collaborations and conduct rigorous, inclusive research with autistic people, the broader neurodiversity community, people with other disabilities, or other marginalized communities.” The toolkit includes resources such as trainings, templates, and sample materials.
- [Accessibility by Design \(AbD\) Toolkit](#) — The Multi-Regional Clinical Trials Center (MRTC) of Brigham and Women’s Hospital and Harvard developed the Accessibility by Design (AbD) in Clinical Research Toolkit to provide institutions, researchers, participants, and patient advocacy groups with tools to support greater inclusion of people with disabilities in clinical research.
- [Doing Research Inclusively: Co-Production in Action](#) — The UNSW Disability Innovation Institute in Sydney, Australia, developed the *Doing Research Inclusively: Co-Production in Action* guidelines, which offer practical strategies for co-producing research with people with disabilities.
- [Peer Support Toolkit to Engage People with Intellectual and Developmental Disabilities \(IDD\) in Research](#) — The Research, Engagement and Advocacy for Community Participation and Health (REACH) Lab provides a toolkit designed for researchers with or without a disability who seek resources on peer-support strategies to include more people with IDD on their research teams.
- [Toolkit on Health Disparities and Disabilities in Research](#) — The Interagency Committee on Disability Research (ICDR) designed a toolkit for federal agencies, federal grantees, and non-federal entities conducting research in health and wellness and implementing health programs and initiatives. The toolkit offers resources on best practices and strategies for including people with disabilities in research.

- [Toolkit for Remote Inclusive Research](#) — The Research Engagement and Advocacy for Community Participation and Health (REACH) Lab developed a toolkit that presents strategies for engaging people with IDD in remote inclusive research during public health emergencies.
- [The UDL Guidelines](#) — CAST provides guidelines for implementing the Universal Design for Learning (UDL) framework, which can be used by educators, curriculum developers, researchers, and parents. The UDL guidelines, which have been adopted in research environments, promote accessibility for all in learning environments.

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