Inclusion

Introduction to the Special Issue on Centering the Voices of People with IDD in the Process and Outcomes of Science

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Abstract

This paper introduces a Special Issue focused on centering the voices of people with intellectual and developmental disabilities in the process and outcomes of science. The article provides an overview of the right to science and how inclusive research can advance that right for people with intellectual and developmental disabilities. An overview of the articles that are part of the Special Issue are provided, as is a framework for approaching inclusive research from a social-ecological perspective.

This Special Issue focuses on advancing inclusive research, or research that centers the voices, experiences, and expertise of people with intellectual and developmental disabilities. The values and approaches embedded in inclusive research build on and align with other traditions, including participatory research, community-based research, and emancipatory research (Ahlers et al., 2021; Barnes, 2002; Bigby et al., 2014; Powers, 2017; Schwartz et al., 2019). All of these approaches explicitly focus on dismantling systems that limit opportunities and supports for the full participation of people with lived experiences in planning, conducting, and disseminating research. One goal of inclusive research is to fundamentally change the dynamic between researchers and people that are researched, creating equitable opportunities for the communities being researched to shape the direction, implementation, and application of research. Inclusive research advances disability justice, recognizes the right of all people to fully participate in the process and outcomes of science, and aligns with efforts to advance diversity, equity, inclusion, and belongingness throughout all aspects of society, including in research (Shogren, in press).

In this Special Issue, one of our major foci was making space for centering the voices of people with intellectual and developmental disabilities. We invited people with intellectual and developmental disabilities that are currently part of inclusive research teams across the U.S. to contribute (see articles by Adams, Bosma, Camacho et al., Linnenkamp, Milne, and Myers, this issue). In creating space for co-researchers with lived experience to share their stories, we sought to elevate the voices of those that also experience marginalization because of their race, ethnicity, language, gender identity, and/or sexual orientation, in the process and outcomes of science. Throughout this Special Issue we use the terminology of co-researchers with intellectual and developmental disabilities to refer to people with intellectual and developmental disabilities who are collaborating in research activities, but do not have formal training or degrees. We refer to academically-trained researchers as those that do have formal training and, typically, do not have lived experience with intellectual and developmental disabilities. We acknowledge these roles can overlap, and we hope they will to a greater extent in the future. We also believe language will continue to evolve, as training, funding sources, policy, and implementation of research continues to evolve and embrace inclusive research practices.

The articles written by co-researchers with intellectual and developmental disabilities went through a peer-review process, as any article submitted to Inclusion. However, we did make modifications to the process. Reviews occurred outside the online system, initially, given accessibility concerns. Each article was peer reviewed separately by an academically-trained researcher and a co-researcher with intellectual and developmental disabilities. Reviewers were asked to address three questions central to a scholarly review: (1) what did you learn from the paper, (2) are there areas that could be expanded on to further make key points about inclusive research, and (3) do you have any feedback on how to elevate the focus on inclusive research in the article? Each author was then provided this feedback and provided the opportunity to revise their article. Each article was reviewed again and decisions were made.

In addition to these articles, we also included a series of articles focused on the implementation of inclusive research. Articles focus on how to advance inclusive research through policy (Forber-Pratt, this issue), as well as throughout three stages of research: planning (Hughes et al, this issue), conducting (Kramer et al, this issue) and disseminating (Parent-Johnson & Duncan, this issue). The concluding paper focuses on the role of people with lived experience in taking research into practice, and the benefits of having implementation of research-based practices led by people with lived experience (Broussard et al., this issue). This set of articles highlights strategies that research, policy, and practice teams have adopted to advance inclusive research. These strategies highlight the systemic changes needed to counter ableist notions of ability that are deeply embedded in the research enterprise about how contributions to science are made (Dolmage, 2017). Such systemic change can advances opportunities and outcomes for people with intellectual and developmental disabilities, including building shared experiences; creating opportunities to learn, grow, and impact others; and enhancing participation (St John et al., 2018). Further, these articles highlight how inclusive research can have a direct and substantial benefit to the communities that are being targeted through the research. Inclusive research impacts society as a whole by ensuring research (and research investments) are addressing real needs identified by the communities the research is purported to benefit (Forsythe et al., 2018; Pellicano & den Houting, 2022).

While the articles in this Special Issue highlight these processes and outcomes, more needs to be known (Jivraj et al., 2014), particularly about the ways that equitable, inclusive research programs are built, implemented, and sustained. The articles by co-researchers in this Special Issue highlight the importance of systemic change and supports for people with intellectual and developmental disabilities for learning about and engaging in research – and provide recommendations for strategies research teams can use to equitably engage co-researchers with intellectual and developmental disabilities. They also highlight how these co-researchers with intellectual disability taught academically-trained researchers about approaches to inclusive research. All of the articles adopt an intersectional lens, recognizing that ableism is closely intertwined with racism and other -isms (e.g., sexism) that continue to feed systems of oppression that sustain inequities designed to maintain the power of the “dominant” culture, including inequities in the right to participate in the process and outcomes of science.

A Social-Ecological Approach to Inclusive Research

In this introductory piece, to frame the articles in this Special Issue, we introduce a social-ecological framework for advancing inclusive research that recognizes the importance of personal and systemic changes to advance abilities, opportunities, and supports for people with intellectual and developmental disabilities and their allies in the research community. We hope this framework can inform ongoing inclusive research. Currently, research structures privilege certain ways of knowing, communicating, and engaging in research, which inhibits the degree to which lived experiences of people with intellectual and developmental disabilities can enhance the research process (Brown & Leigh, 2020; Dolmage, 2017). These issues that are even further exacerbated for those with intersectional identities (Johnson et al., 2021). A social-ecological approach must address these barriers as well as create pathways for training and career development for people with intellectual and developmental disabilities to pursue research activities of their choosing (Shogren, in press).

Advancing inclusive research requires challenging systemic barriers rooted in ableism, racism, and other -isms (e.g., sexism) to build abilities, opportunities, and supports for people with intellectual and developmental disabilities to participate in all phases of research. Social-ecological models of disability, such as that adopted by the International Classification of Functioning (World Health Organization, 2007) and the American Association on Intellectual and Developmental Disabilities' terminology and classification manual on intellectual disability (Schalock et al., 2021) recognize disability as a state of functioning resulting from the interaction between personal capacities and environmental or contextual demands. Such models hold that when people with disabilities experience a mismatch between their personal capacities or abilities and environmental or contextual demands, this creates a need for supports.

In applying this approach to inclusive research, supports can include breaking down systemic barriers as well as creating personal supports that empower people with intellectual and developmental disabilities to build abilities and access opportunities to participate in all phases of the research process. For example, Linnenkamp (this issue) highlights the importance of ensuring a fit between the strengths, interests, and abilities of researchers with intellectual and developmental disabilities and the tasks they perform on research projects. Further, Adams (this issue) and Milne (this issue) express the need for people with intellectual and developmental disabilities to have access to learning opportunities about research aligned with their learning preferences, support and communication needs, and that center their experiences as essential to all phases of the research process. Only then can equitable, culturally sustaining learning opportunities that build abilities and create career pathways for people with and without intellectual and developmental disabilities to participate in inclusive research be advanced. Similarly, in practice, these same inclusive principles can be used to create career opportunities and advance outcomes for people with disabilities who are delivering and receiving research-based interventions, as highlighted by Broussard et al. (this issue).

Equally important are environmental opportunities, or equitable opportunities to participate in the research process. This involves policy supportive of inclusive research as highlighted by Forber-Pratt (this issue), education and career pathways for people with intellectual and developmental disabilities as highlighted by Linnenkamp (this issue) and Adams (this issue), and communication about the outcomes of inclusive research, as highlighted by Bosma (this issue). This Special Issue highlights the need for recognition of inclusive research projects and teams within university settings and provides recommendations and examples of equitable methods for supporting inclusive research across all types and stages of research.

Inclusive research practices – when systemic barriers are removed and personal and environmental supports are in place – can be applied to any type (e.g., basic, applied) and stage (e.g., exploration, development, efficacy testing) of research. In doing so, research lines can be enhanced by lived experiences from the start. Environmental opportunities must move beyond tokenistic approaches (e.g., unequally resourced "volunteers" or "consultants") and instead create equitable opportunities that make the systemic changes needed to redefine ability and participation in research processes (Forber-Pratt, this issue).

Finally, new and different supports must be infused throughout the research process, again changing and challenging the current system. Building culturally sustaining research practices into inclusive research can support the integration of the lived experiences of, for example, Black girls with disabilities into research about their experiences in the schools and the criminal justice system (Annamma, 2017) or LQBTQIA+ people with intellectual disability into research on supports for gender self-determination (Hughes, 2022). As highlighted in the voices of co-researchers with intellectual and developmental disabilities in this Special Issue, people must also have access to language, technology, and other supports needed to fully engage in all phases of the research process (Adams, this issue; Camacho et al., this issue; Myers, this issue). These personal supports must be aligned with each person's needs, preferences, and roles and be situated in responsive systems that recognize that all people need supports and that the need for support is not justification for marginalization (Bosma, this issue).

To summarize, an inclusive research agenda can operate in the context of a wide range of research projects and activities, but the ultimate goal of inclusive research is to advance disability justice and the right to self-determination in research. Centering the lived experiences of people with intellectual and developmental disabilities requires systemic change that challenges ableism, racism, and all other -isms in society. It also necessitates the creation of pathways for learning and engagement in all phases of the research process, with opportunities and supports for people with lived experience to choose and direct career pathways aligned with inclusive research. Focusing on building abilities, creating opportunities, and enhancing supports within research systems for academically-trained researchers as well as co-researchers with intellectual and developmental disabilities and other marginalized identities is essential to inclusive research.

Phases of the Research Process

As noted, research can be used to advance many outcomes, and inclusive research can support outcomes that are aligned with the goals of the communities that are the focus of research. Inclusive research can also advance a focus on diversity, equity, inclusion, belonging, and justice. Centering the perspectives and expertise of those with lived experience advances the right to science and can be infused in all types and stages of research (Chapman & Wyndham, 2013). It is beyond the scope of this paper to review all the different types of research (e.g., basic, applied), types of research designs (e.g., qualitative, quantitative, mixed methods), stages of research (e.g., exploration, development, efficacy, implementation). However, as is illustrated in the articles that make up this Special Issue, co-researchers with intellectual and developmental disabilities can meaningfully contribute to all types and stages of research, if an inclusive, social-ecological approach is adopted.

To organize our discussion of phases of research, we adopt a broad, plain language framework to define three phases of research - planning, conducting, disseminating. Table 1 provides an overview of key activities within each of these phases. Traditional research programs train researchers to be involved at each of these phases, however each phase can be enhanced by including team members with different training and areas of expertise that pertain to specific stages as highlighted by Hughes et al. (this issue), Kramer et al. (this issue), and Parent-Johnson & Duncan (this issue). People with intellectual and developmental disabilities can learn about and engage in different roles throughout the research process based on preferences, expertise, interests, and experiences. Within each phase, there are specific steps and activities that will occur and specific systemic and personal supports for learning and engaging may be needed at different phases. Researchers have found an impact of including co-researchers in funded projects on research questions, the selection of interventions to compare, decision making about study outcome measures, and recruitment strategies (Forsythe et al., 2018). Funders are increasingly exploring ways to engage people with lived experience in multiple ways across all funded projects (see Forber-Pratt, this issue).

During the planning phase, a key activity is building the team (i.e., identifying the partners including the partners, including partners with lived experience, that will support different activities across the phases of research). This is a natural time to challenge systemic barriers and ensure there is a focus on diversity, equity, and inclusion in establishing the team, defining roles, creating communication systems, and acknowledging and centering different ways of knowing and engaging in research. Team building creates the context to generate ideas for research, this may be aligned with generating ideas for a proposal for funding or doing environmental scans to key issues in the communities that are the focus of research. During these activities, people with lived experience can not only share their experiences but also serve as cultural brokers, bringing together community members to share experiences and needs (Suarez-Balcazar et al., 2014). This can lead to establishing research questions that will be targeted to the needs of the community being studied and support collaboration during the development of the research design. In designing a research study, new and different supports and areas of expertise (e.g., statistical design, implementation scientists, community activists) can come together to select a design that both addresses the questions and is also feasible, acceptable, and can be implemented in the context and with the communities being targeted. Further co-researchers with intellectual and developmental disabilities can support the team to explore any systemic or personal bias that has characterized previous research or research methodologies that should be evaluated in designing the study. In this Special Issue, Hughes & Schwartz (this issue) provide rich examples of planning inclusive research from two separate inclusive research projects.

Next comes the conducting phase, when the design established during the planning phase is implemented. Depending on the type and stage of research this might involve conducting exploratory research (e.g., focus groups, surveys, scraping data), testing different interventions (e.g., determining what intervention is most effective in enhancing outcomes in the community) or exploring mechanisms that might underly a health disparity in a specific population. This could also involve scaling up and testing the broader impacts of implementing new policies or approaches in a system (e.g., disability services, health, education). Essential to this step, as well as during the planning phase, will be ensuring that the research being conducted builds on research that has also adopted inclusive and anti-ableist and anti-racist approaches (see Scott & Shogren, in press). For example, identification of systemic biases in a policy or body of research, such as disability services and supports (Friedman, 2020; Shippee et al., 2021), might lead to a need to implement a new method of researching the issue. The perspectives of those with lived experience as co-researchers can bring forward these issues and identify possible solutions. Inclusive research teams must strive to challenge their own biases and be open to new and different approaches. Lived experience can also inform the most effective and culturally responsive outcome measures, identifying what is relevant and effectively integrates best practices in culturally responsive assessment (Goode et al., 2017). A justice-oriented lens can shape the implementation of the research design, the data collection, and the data analysis. For example, QuantCrit (Garcia et al., 2018) has emerged as a way for research teams to consider systemic bias and marginalization in the data analysis process. Kramer et al. (this issue) highlight approaches to conducting inclusive research from two projects, one focused on assessment and one focused on intervention.

The final phase, dissemination, involves sharing research findings to impact research, policy, and practice. The dissemination phase introduces new opportunities to leverage a range of experiences and areas of expertise to create dissemination approaches, materials, and strategies that targets different stakeholders and community members to influence future research, policy, and practice. Effective, inclusive dissemination can address critical issues related to plain language descriptions of findings, data visualization to enhance accessibility, and consideration of implementation needs to make change in policy and practice. During this phase, consideration of ways to enhance accessibility and consider anti-ableist approaches to centering who has the power to use research findings to make change are essential to inclusive research. Parent-Johnson & Duncan (this issue) describes their approach to inclusive dissemination and Broussard et al. (this issue) highlights how people with lived experience can drive the process of putting research into practice.

Challenging systemic barriers across all phases of research can allow for a greater focus on increasing equity and centering the experiences of people that have been marginalized based on ability, race, ethnicity, sexual orientation, and gender identity in our current systems, including research systems. Key issues will be challenging inequities in funding as existing structures do not always fund inclusive research in ways that allow full participation and inclusion across all research phases as well as equitably compensating people with lived experiences. Another key issue will be working with research institutions to ensure equitable compensation and career pathways for people with non-traditional but equally valuable experience and training. Finally, ensuring access to and development of needed supports, including technology and plain language materials throughout all phases of research will be critical.

Action Steps for Advancing Inclusive Research

This Special Issue seeks to build on long-standing work by research teams across the world that has demonstrated the feasibility and impacts of inclusive research on advancing equity and justice for people with intellectual and developmental disabilities (Hughes et al., 2020; Kramer et al., 2011; Morgan et al., 2015; Schwartz et al., 2019; St John et al., 2018). The goal is to further efforts to center the voices of people with lived experiences and highlight strategies to create personal and systemic supports for inclusive research. People with intellectual and developmental disabilities have the right to self-determination in the process and outcomes of science (Shogren, in press). By challenging systemic barriers, building personalized supports, and creating equitable training and career pathways across all phases, types, and stages of research we can establish inclusive research as the expectation, not an exception, as highlighted by the co-researchers with intellectual and developmental disabilities featured in this Special Issue.

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Table 1

Phases of Inclusive Research and Activities within Phases

Phase	**Activities**
Planning	o Team Building ▪ Identifying Partners ▪ Role Definition and Expectations ▪ Working Styles o Idea Generation ▪ Gathering Community Perspectives ▪ Exploring Bias in Existing Research o Research Question Development ▪ Determining Type and Stage of Research o Research Design Development
Conducting	o Implementation of Research Design ▪ Exploring Bias in Implementation o Data Collection ▪ Ensuring culturally responsive assessment o Data Analysis ▪ Justice-oriented lens
Dissemination	o Accessibility - Plain Language and Data Visualization o Communication with: ▪ Researchers ▪ Policy Makers ▪ Practitioners ▪ Community Members o Advancing Equity in the Use of Outcomes of Inclusive research