Intellectual and Developmental Disabilities

Advancing Inclusive Research in Intellectual and Developmental Disabilities: Building Community and Supports for Participation

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Abstract:	People with intellectual and developmental disabilities are often excluded from equitable inclusion in the development and execution of research. Despite increased advocacy for inclusive research over the last decade, the widespread use of inclusive research practices remains limited. There is a need for systemic change to foster the inclusion of people with intellectual and developmental disabilities in planning, conducting, and disseminating research. This paper describes actions taken by a research group to make system changes to empower and support people with intellectual and developmental disabilities to learn about and engage in research. It highlights ongoing work that is needed and possible ways to advance systemic change.

Advancing Inclusive Research in Intellectual and Developmental Disabilities: Building Community and Supports for Participation

Abstract

People with intellectual and developmental disabilities are often excluded from equitable inclusion in the development and execution of research. Despite increased advocacy for inclusive research over the last decade, the widespread use of inclusive research practices remains limited. There is a need for systemic change to foster the inclusion of people with intellectual and developmental disabilities in planning, conducting, and disseminating research. This paper describes actions taken by a research group to make system changes to empower and support people with intellectual and developmental disabilities to learn about and engage in research. It highlights ongoing work that is needed and possible ways to advance systemic change.

Keywords: inclusive research, intellectual and developmental disabilities

While people with intellectual and developmental disabilities have long advocated for their right to be involved in choices and decisions about their lives, full and equitable participation of people with intellectual and developmental disabilities in all aspects of research that impacts their lives remained limited (McDonald et al., 2021). Historically, people with intellectual and developmental disabilities were either excluded from research or only viewed as participants or beneficiaries of research studies designed by others. While there has been a growing focus on advancing greater inclusion of people with intellectual and developmental disabilities in informing research priorities, often through advisory roles, people with intellectual and developmental disabilities are rarely equal partners in designing, implementing, and disseminating research studies (Stack & McDonald, 2014). However, people with intellectual and developmental disabilities have called for opportunities to engage in the research process as well as to access learning opportunities about research that align with their strengths, interests, and abilities (Adams, 2024; Linnenkamp, 2024; Milne, 2024).

Over the last decade there has been an international movement co-led by people with intellectual and developmental disabilities and their allies to advance inclusive research where people with and without intellectual and developmental disabilities collaborate and share power to identify and implement research studies to advance meaningful outcomes for the disability community (Walmsley et al., 2018). The term ‘inclusive research’ has been defined in past literature as research conducted with co-researchers with disabilities (Walmsley, 2004). Early research on inclusive research has been conducted all over the world, including in the United Kingdom, Australia, and the Netherlands (Bigby et al., 2014; Embregts et al., 2018; Frankena et al., 2019; O'Brien et al., 2014), and there is a growing body of research in the United States (Kramer et al., 2011; Kramer et al., 2023; Nicolaidis et al., 2019; Schwartz et al., 2020). All of this work emphasizes the importance of adopting frameworks for inclusive research that break down barriers and build effective supports for the sharing of power in research between people with and without intellectual and developmental disabilities. Walmsley et al. (2018) suggest that inclusive research can shift our current paradigm of academics without lived experience leading research to academic researchers becoming a “means to an end, no longer allies, but expert consultants who carry out the wishes of people with a disability” (p. 753).

Inclusive research frameworks offer practical and theoretical guidance for researchers to consider as they establish networks and supports for inclusive research at their institutions and within their research teams. For example, Frankena et al. (2019) described a process of convening more than 50 experts in inclusive health research with and without intellectual and developmental disabilities to develop a consensus statement framed around four broad areas: (a) attributes, (b) potential outcomes, (c) reporting and publishing, and (d) future research directions. The consensus statement offers practical steps for how to engage people with intellectual and developmental disabilities on university research teams, from establishing a positive, collaborative, inclusive climate, to recruiting researchers, designing and facilitating a study, generating data, analyzing results, and dealing with practicalities. Importantly, the authors acknowledge the continuously evolving nature of this work and the expectation that continuous discussion and adaptation will take place as new knowledge and experience arise.

Similarly, the framework for Community Based Participatory Research developed by AASPIRE (Nicolaidis et al., 2011) highlights the role of equal partnership of autistic community members and academic researchers throughout the stages of developing, implementing, and disseminating research studies. In this model, academic researchers are responsible for ensuring the research is rigorous and academically relevant, while community members ensure the research is respectful, accessible, and socially relevant. AASPIRE also defined guidelines for engaging autistic adults as members of research teams and focus on defining partner roles, creating a process for sharing power, and building trust (Nicolaidis et al., 2019).

Schwartz et al. (2020) developed a conceptual model illustrating factors that foster and maintain inclusive research collaborations. The model was developed using grounded theory methodology based on input from researchers with and without intellectual and developmental disabilities who had sustained inclusive research partnerships. The authors found that the values, experiences, and motivations of the researchers with and without intellectual and developmental disabilities as well as their commitment to accessibility of structures and processes that promote meaningful input from researchers with intellectual and developmental disabilities are foundational to sustainable inclusive research partnerships. Further, there is a reciprocal relationship between accessibility of processes, active involvement of researchers with intellectual and developmental disabilities, and responsivity to input by all team members; together this can lead to high levels of trust and familiarity among research teams that create strong and lasting systems for equitable collaboration. Lastly, Embregts et al. (2018) identified core competencies integral for collaboration between people with and without lived experience with intellectual and developmental disabilities in inclusive research using feedback from researchers with and without intellectual and developmental disabilities, policy makers, and educators. The five core competencies included: cognizance of skills and support needs, collaborating in a way that everyone involved can contribute, fostering mutual relationships, communicating, and being aware of the impacts of inclusive research.

As the above research demonstrates, there is a growing focus on inclusive research that engages people with intellectual and developmental disabilities as leaders in all phases of the research process (Walmsley et al., 2018). However, there remain several gaps in the current literature on inclusive research. For example, training opportunities for individuals with intellectual and developmental disabilities to acquire skills and knowledge to engage in inclusive research have not been robustly addressed, with exceptions (Ausderau & Health Research Engagement Development Team, n.d.; García Iriarte et al., 2023; Strnadová et al., 2014; White & Morgan, 2012). Further, ways to build community and challenge and dismantle systemic barriers to inclusive research across all types and stages of research has not yet been fully addressed in existing frameworks limiting sustained use of inclusive research practices (Shogren, 2023). Researchers with disabilities have identified systemic barriers to full engagement in the research process, including access to training, technology, and other supports that are aligned with personal needs, preferences, and roles (Bosma, 2024; Camacho et al., 2024; Myers & Schwartz, 2024). Other systemic barriers include a lack of recognition of the importance of lived experience in the research process as well as the need for the creation of career pathways in research for people with intellectual and developmental disabilities (Shogren, 2023). In this paper we describe efforts undertaken by our research team to address these systemic issues and make sustained change in intellectual and developmental disability research at our university and beyond. We hope this approach can generate ideas for other teams, create new collaborations, and advance ongoing change.

Building An Inclusive Research Ecosystem

Creating a Shared Definition of Inclusive Research

Our research team consists of multiple members with and without lived experience with intellectual and developmental disabilities. All team members bring expertise relevant to disability research, including expertise in disability advocacy, disability policy, school and community-based supports and services, project management, and research design and data analysis. We share a commitment to advancing inclusive opportunities for people with disabilities aligned with their interests, values, and preferences to benefit *all* team members and the quality of intellectual and developmental disability research. We have increasingly been exploring ways to advance the integration of inclusive research principles not only into our research team, but also across all research projects at our [Masked for Review] Center and across other research, policy, and practice groups that we partner with; this has impacted our hiring and staffing priorities with a focus on hiring and engaging more people with lived experience with disability as equal members of our team. We have sought to build an inclusive and collaborative culture where shared decision-making is a priority and where all people's support needs and areas of expertise – including our team members with lived experience – are valued and a part of all decisions. Project direction and management decisions are made collectively, program and intervention materials are developed iteratively, and all team members share and consider each other's ideas and perspectives during team meetings. We seek to build a culture where inclusive research is not an add-on to existing activities but a foundation for our growth as a Center and the development and implementation of projects. We have also actively sought out funding opportunities to advance the scope and support for this work, including growing our team.

As a first step to expand inclusive research opportunities at our Center and beyond, our team developed a shared definition and principles for our approach to inclusive research, with the goal of using this definition and principles to pursue new projects as well as expand the network of people that are aware of, embrace, and advance inclusive research practices. We used a collaborative approach to develop our definition and principles. Specifically, a team of 13 people at our Center came together to work to create the shared definition. This included two academically trained faculty members, three postdoctoral fellows in disability research, two graduate students in disability research, two project management staff, one community liaison with lived experience as a family member, and three researchers with lived experience as people with intellectual and developmental disabilities. One of the researchers with lived experience had transitioned to research after a long career in self-advocacy and had served as co-Principal Investigator on research grants since the transition, and two others were newer to the team and the research field. The senior faculty member and the researcher with lived experience led the team, jointly. In working together to create our definition of inclusive research, team members with expertise in reviewing and synthesizing literature gathered existing definitions of inclusive research from the literature, team members with lived experience participated in identifying how plain language could be used to describe key concepts and talked to people with lived experience outside our research team (e.g., a local self-advocacy group) about what research meant to them, and team members with expertise in scientific writing coordinated and organized drafts in an iterative approach for review by the entire team. Throughout the process, we met as an entire team, reviewed each component of our work, and came to shared decisions about moving forward. Over multiple meetings we refined our shared definition and principles that should be followed in applying this definition. We ensured that all team member voices were heard through explicitly providing space in meetings for each member to share their thoughts. We actively discussed and debated the best balance between plain language and research terminology to reach multiple audiences and decided on the importance of a definition that reflected plain language and associated principles that were more technical that could be used to expand the understanding, implementation, and impacts of inclusive research across multiple end-users. Table 1 provides our working definition and principles. We anticipate this definition will continue to grow and evolve. It also provided a foundation for the next step in our work, to attempt to build an inclusive research network that was broader than just our Center.

Building an Inclusive Research Network

As a next step, and with support from a contract awarded to our research group to build capacity for the engagement of people with intellectual and developmental disabilities in research about their lives, we sought to expand our connections to other researchers, policy makers, and advocates outside our Center interested in learning more about expanding their focus on inclusive research within our state, although we hope to establish national and international opportunities over time. We initiated a monthly group meeting that focused on building community and mutual supports for inclusive research. Multiple recruitment methods were used to identify key partners across the state, including a snowball nomination process, where we reached out to key leaders and collaborators at our university, state agencies, disability advocacy organizations, self-advocacy organizations, and state-level funders. We asked people to nominate themselves for participation and invite others with shared interests. A major focus of convening this group was to build capacity to expand the integration and impacts of inclusive research throughout all types and stages of research impacting people with intellectual and developmental disabilities.

Twenty people initially signed up for the group, representing research centers, community health centers, self-advocacy organizations, and state-level health and disability organizations, and this number has grown to 33 people who receive communications about the group. The group is currently meeting monthly with an average of 14 participants per month. The network is structured around two types of sessions, which rotate: (a) sharing information about existing research programs and priorities to facilitate collaborative work to advance inclusive research within each of the participating organizations or research programs and (b) defining a mission, shared values, and action steps to advance opportunities for inclusive research. Many researchers participating in the inclusive research network meetings identified an interest but a lack of knowledge of how to initiate inclusive research and navigate systemic barriers (e.g., lack of funding, lack of infrastructure within university, state, and disability systems). Thus, a first step in defining our mission, values, and actions was to learn about frameworks for initiating and sustaining inclusive research. Then, a next step was to learn more about each other's research and identify actions for moving toward inclusive research that covered the broad range of research programs represented (e.g., educational research, disability services research, neurobiology of disability research, community-engaged research). For example, early meetings focused on presenting our definition and principles of inclusive research and brainstorming on needed expansions or edits. We then shifted to having members share their research, policy, or funding priorities to advance understanding of overlapping and distinct priorities; this included traditional academic research teams, as well as self-advocacy organizations, and community disability organizations. As many of the research teams had not yet initiated inclusive research, but were expressing an interest, we used sessions as opportunities to provide input on steps that could be taken to advance inclusive research as well as share ways that our inclusive team operated and navigated around systemic barriers. After that, we reviewed research on inclusive research frameworks, such as those presented above, and began to develop our own guidelines.

A major, current focus has been on how to initiate inclusive research (e.g., find funding, find partners, navigate systemic barriers) and how this group can facilitate connections between researchers and people with intellectual and developmental disabilities who want to become researchers. This iterative process is leading to new collaborations, a growing awareness of and identification of steps and collaborations to advance inclusive research, and new targets for funding priorities and activities. Building on the definition of inclusive research that our Center established, the Network has worked to create a mission and vision statement for itself and define steps to initiate collaborative inclusive research within the network. The process for developing the vision and mission statements began with looking at vision and mission statements from other relevant organizations and groups. Two network meetings were used as brainstorming sessions for the group to collectively generate ideas of key points and common themes about what vision and mission statements should say. Finally, from the detailed notes from these discussions, drafts of statements were created to capture key ideas, which Network members voted on. Versions with the most votes were further discussed and iterated on with the entire network before being finalized. The working mission and vision statement are presented in the bottom half of Table 1. Current efforts are focused on creating a "handbook" that can be shared to support teams to access and share resources that support (a) hiring and supporting researchers with lived experience, particularly in academic settings, (b) navigating IRB requirements and procedures, and (c) identifying funding to support inclusive research teams. The goal is to create a hub for resources on inclusive research and begin to map inclusive research opportunities to build greater connections and trust between researchers with and without lived experience to expand teams and networks.

Sustaining an Inclusive Research Network

Our research team plans to sustain this inclusive research network over time, with a long-term focus on changing systems and removing barriers to inclusive research within the university, community, and policy contexts, and advocating for change within current exclusionary research frameworks. We also hope to expand beyond state-level efforts and better connect with other groups and partners across the world. It is important to our research group that our network spans a wide range of research, from basic science to translational and applied community research, to recognize the range of opportunities for inclusive research. However, ongoing planning for addressing and understanding the diverse needs of different research programs is needed. Overall, our inclusive research network hopes to move beyond convening groups to engaging groups through longer-term partnerships and sustained change. We are also targeting ways the network can support the creation of job and career pathways for people with intellectual and developmental disabilities who want to become researchers, with the goal of the network ultimately providing a hub for supporting the infusion of inclusive research practices and inclusive researchers with and without lived experience into grant proposals and grant funded programs. We hope to provide a way to “match” people with lived experience with disabilities with opportunities for roles on research teams, building the supports needed for successful, funded, inclusive research. For example, we asked Network members to share information about inclusive research opportunities using a mapping system to identify opportunities and address barriers to building collaborations and long-term relationships leading to positions on research teams.

Co-Creating Training Opportunities

One issue that has emerged in our work and in the work of our inclusive research network is how to find and connect researchers interested in inclusive research and people with lived experience with intellectual and developmental disabilities who want to be researchers. Unfortunately, many people with intellectual and developmental disabilities are not afforded opportunities to learn about research and to participate in research training programs. It is important to note that this is not because of a lack of interest or ability, as people with intellectual and developmental disabilities have communicated their interest, but instead because of systemic barriers that limit access for people with intellectual and developmental disabilities to training on research methodologies, team science approaches, and opportunities to meaningfully participate because of low expectations (Vega-Córdova et al., 2020). We acknowledge that there is debate in the field about whether maintaining existing structures for participating in research maintains ableist and hierarchical structures (Milligan et al., 2019) and our inclusive team believes systemic change to advance anti-ableist approaches in the research enterprise is necessary and essential. However, we have also consistently heard from our research team members with lived experience and other self-advocacy groups about the importance of having access to information, and that current information about research is often not accessible or meaningful (Adams, 2024; Linnenkamp, 2024). This guided our development of the Inclusive Research Learning Series, rooted in our belief in the need to advance the right to not only the outcomes of science, but also the process of science (Shogren, 2023).

Thus, our inclusive research team developed an Inclusive Research Learning Series is designed to directly engage people with intellectual and developmental disabilities in learning about research and creating opportunities for them to participate as researchers on projects aligned with their interests and values. Our inclusive research team leveraged research-based strategies from the field, our own research, and our own lived experiences on how to make content accessible and meaningful for people with intellectual and developmental disabilities. The pilot version of the Inclusive Research Learning Series consists of 16 one-hour sessions organized into six learning modules. Table 2 provides the objectives for each module and session and highlights how the Inclusive Research Learning Series integrates learning and application activities related to planning, conducting, and analyzing data from a World Café organized by the emerging researchers (the term we use to refer to participants in the learning series).

We used a World Café as the primary application activity during the Inclusive Research Learning Series; however, when the series is replicated, we believe other types of research projects could also be integrated into delivery. We chose the World Café because it is a model that centers the voices and perspectives of those most familiar with and affected by the issues under study and engages community members in “constructive dialogue, accessing collective intelligence, and creating innovative possibilities for action” (Brown & Issacs, 2005, p. 3). Further, the World Café approach afforded emerging researchers the opportunity to plan, conduct, and analyze research in a matter of months, connect with participants in an authentic way, and amplify the voices of people with disabilities.

The specific steps taken to develop the content, format, and delivery of the Inclusive Research Learning Series are described in the following sections. Thirteen emerging researchers participated in an initial pilot of the Inclusive Research Learning Series. Emerging researchers were identified through individual and organizational outreach to disability partners throughout the state. The average age of emerging researchers was 35 years old. Six were male, five were female, and two identified as non-binary. Race/ethnicity of the group was primarily White (n = 10) and not Hispanic (n = 12). Emerging researchers had a range of educational experiences including (a) formal schooling but no high school diploma or GED (n = 1), (b) holding a high school diploma or GED (n = 1), (c) some college but no degree (n = 4), (d) holding an Associate Degree (e.g., AA, AS; n = 5), (e) holding a Bachelor’s Degree (e.g., BA, BS; n = 1), and (f) holding a Graduate Degree (e.g., MS, MA, PhD; n = 1). Most emerging researchers identified as having autism (n = 10), and/or a mental health disability (n = 8). At the start of the learning series, most emerging researchers self-reported level of comfort with research ranged from somewhat comfortable (*n* = 7) to comfortable (*n* = 4) and very comfortable (*n* = 2).

Content Development

The overall goal of the learning series is to build the knowledge, abilities, and confidence of people with intellectual and developmental disabilities related to inclusive research practices that lead to opportunities to engage on inclusive research teams. For this reason, our inclusive research team used an iterative process to identify key topics related to research and inclusive research practices by reviewing the literature, meeting to discuss ideas, and prioritizing key content to be covered. We used a similar approach to the development of our Center's shared inclusive research definition. We brought together our team and created a shared decision-making culture where we discussed all topics as a team at weekly meetings, and then identified sub-groups to work on specific activities such as developing content. Researchers with lived experience were deeply involved in subgroups, bringing their lived experience into the development of examples and the presentation of the content in all sessions and partnering with team members with expertise in curriculum development. This process led the identification of 12 key concepts that would be targeted across the modules: research, inclusive research, research ethics, quantitative research, qualitative research, research questions, hypotheses, participant recruitment, data collection, data analysis, and dissemination. The alignment of each of these topics with the modules is provided in Table 2. While Table 2 provides content in a more traditional academic format, in practice, each of the specific sessions includes clear definitions of the content in plain language throughout to make it accessible to all team members.

Based on adult learning literature (e.g., Hagen & Park, 2016) that highlights the importance of having opportunities to apply what is learned, we also focused on identifying ways to create authentic, hands-on experiences with implementing each of these concepts. Adult learning theory suggests that adults learn most effectively when they apply their learning to real-world scenarios (Knowles et al., 2005), indicating the importance of developing our inclusive research learning series around a framework of opportunities for application of knowledge (Nilson, 2016). Researchers with lived experience on our team developed examples and presented this content drawing on their lived experience during sessions. And, to create deep opportunities for engagement of the emerging researchers during the learning series, during each module, emerging researchers apply the content learned to organizing, planning, and analyzing data from a World Café that occurs in the middle of the learning series with real participants selected to align with the research questions identified by the emerging researchers.

Materials Development

After establishing the key content, concepts, and session and module objectives, our inclusive research team began designing materials aligned with the session objectives, using adult learning principles, Universal Design for Learning (i.e., providing multiple means of engagement, representation, and action and expression; CAST, 2018), and plain language, so that all emerging researchers could access the content in multiple ways. Each session had (a) a PowerPoint slide deck, (b) a facilitator's guide detailing the content to be covered, activities, examples, discussion questions, and approximate timing of each slide to guide our team members with and without lived experience with intellectual and developmental disabilities in communicating content, leading discussions, and sharing examples, and (c) a preparation guide specifying what emerging researchers should complete before the session and questions they should be prepared to answer/discuss during the session. Researchers with lived experience were instrumental in all stages of materials development and provided insights on the specific examples that would be directly relevant to the objectives of the session, often drawing from their work on other projects. They also gave valuable input on plain language use and the quantity of content so as not to overwhelm emerging researchers with too much detail. For example, in Session 12 on data analysis, researchers with lived experience selected the examples (i.e., visualizations and interview excerpts) that would be used to walk emerging researchers through different quantitative and qualitative analysis approaches. Talking points in the Facilitator's Guides about what the data communicated were written in their words. Additionally, content included in initial drafts was often omitted at the suggestion of team members with lived experience, to streamline and ensure time to process and grasp the key concepts. With this input, , we have found that the content in Table 2 could be delivered in 60 minutes and emerging researchers reported learning and gaining confidence in applying the concepts.

Prior to beginning the content-focused session, two introductory sessions were designed to complete logistical tasks and prepare emerging researchers for the learning series (i.e., Pre-Session A and Pre-Session B; see Table 2). The purpose of Pre-Session A, which was an individual meeting between each emerging researcher and leadership team members with and without lived experience with intellectual and developmental disabilities, was to ensure all technology needs were met and individualized supports were in place for participating virtually, as, in our pilot, we delivered the learning series virtually. Materials for conducting Pre-Session A focused on practicing the features of each software (i.e., Zoom, Padlet, and Qualtrics) that would be used in the Inclusive Research Learning Series, as well as planning for individual support needs. For example, we planned with our emerging researchers who used augmentative and alternative communication (AAC) devices to learn preferences and recommendations for communication supports during group discussions and other activities. We also introduced the Preparation Guides that were shared for each session with all emerging researchers to allow for preparation and reflection in advance of the sessions. These meetings were one-on-one. Pre-Session B, the first full group learning series meeting, was intended to orient the group to the purpose of the learning series, introduce all emerging researchers and team members, engage in team and community building, and provide a structure for a pre-series content knowledge and confidence check to gauge where each emerging researcher was in their understanding and confidence with the 12 concepts being targeted throughout the series.

In the sessions following the two introductory sessions, we adopted a structured format that was repeated across each session (i.e., agenda review, icebreaker, concept introduction, concept application, summary) to support engagement and learning. Within each module, the first session focused on introducing and building a shared understanding of one or more of our 12 concepts with applications to each emerging researcher's life or previous experience and the second session focused on applying what was learned about the concept in the previous session to an activity related to the World Café. For example, Module 2 (Sessions 3 and 4) of the learning series focused on planning and designing a research project/World Café. Within Module 2, Session 3 introduced concepts related to the planning stage of a research study and the key considerations that researchers make, including (a) research questions, (b) participants, and (c) timeline. Session 4 was structured to apply these concepts and skills by determining research questions the emerging researchers want to answer through the World Café, identifying participant groups that could best answer those questions, and considering their specific timeline for planning and implementing the World Café. The following Modules (Modules 3 – 6) focus on learning and executing the components to conducting the research study (e.g., the World Café), analyzing the data, and disseminating the findings.

The development of these materials was iterative, with multiple rounds of feedback on each document from multiple team members with both research expertise and lived experience expertise. Adjustments to materials were also made after each session based on how the session went, and responses and feedback from emerging researchers including their review of the session and if it advanced their knowledge and confidence with the concept(s) being targeted. For example, when content on participant recruitment was initially covered in Module 3, feedback from emerging researchers on their post-module survey indicated that they were still not comfortable with the concept. Therefore, content for Module 4 was revised to include additional description and examples of participant recruitment.

Learning Series Design Features

In developing the content and materials, we sought to utilize best practices to promote access to and engagement with the content as described previously. We adopted universal design for learning principles (UDL; CAST, 2018) as well as sought to use key principles of instructional design (Housel, 2020) and adult learning (Nilson, 2016). For example, a key focus was ensuring that all content supported activating, demonstrating, and applying knowledge, based on the idea that learning is more meaningful when learners are engaged in real-world topics relevant to their own lived experiences. Researchers on the inclusive research team brought their lived experiences and expertise to the development process and specifically shared ways to communicate content that aligned with their needs and experiences, pushing the team to think beyond how concepts were described in published texts and literature on research processes and focus more on making content meaningful for people with intellectual and developmental disabilities. To ensure we were still delivering key content, we used instructional design principles to support clear learning objectives and scaffolds and centered the strengths and life experiences of the emerging researchers (Housel, 2020).

We also adopted the practice of consistency and predictability in the structure of each session and module. For example, using the UDL principle of engagement, we used the same broad framework for each session (e.g., starting each learning session with a team building activity and ending each session with a reflection, review of main topics discussed in the session, and next steps for the following session). Using the UDL principle of representation (e.g., promote the understanding of the material, clarify vocabulary and terms), we carefully considered language choices in our learning series. The learning series content was written in plain language, which is defined in the Plain Writing Act of 2010 as “writing that is clear, concise, well-organized, and follows other best practices appropriate to the subject or field and intended audience.” Our Center has a plain language team, and members served on our development team. We were oriented around the belief that plain language benefits everyone and was particularly important given the complex concepts that are a part of the research process. Using the UDL principle of multiple means of action and expression, we supported multiple modalities for communication (e.g., Zoom, Padlet) and emerging researchers could communicate in multiple methods (e.g., verbally, using chat, using emojis, using their AAC device).

Delivery Format

The learning session materials were designed so that they could be implemented in-person or virtually in a flexible time frame (e.g., weekly, twice a month, monthly) based on implementation needs. In our pilot, sessions were delivered twice a month. There was equal participation in delivering all content across all of our team members (e.g., academically trained researchers, researchers with lived experience, postdoctoral fellows, graduate students). Practice sessions were held prior to each session to promote fluency with content and delivery in a group setting. The decision to implement virtually was made by our inclusive research team given persistent transportation issues as well as ongoing concerns by some members of the disability community about health needs, particularly related to hosting the World Café. This led to Pre-Session A, which focused on ensuring technology access and supports were in place. We also built in a review of Zoom expectations at the start of each session (e.g., reviewing practices like allowing all members to communicate, respecting each person's contributions, muting when not speaking, using respectful communication strategies when people used various modes to communicate [e.g., AAC devices, chat]). We also hosted a breakout room that could be accessed at any point during each session if any emerging researchers were having technology issues, wanted to further discuss a topic, or needed a break from the large group environment.

Advancing Ongoing Growth and Career Pathways

The hope is that, once fully developed and iteratively refined during the pilot, this series can be delivered more broadly to open training opportunities to people with intellectual and developmental disabilities that target key aspects of the research process and that such training opportunities can be linked with participation on inclusive research teams. The goal is to build capacity as well as shape available opportunities by advocating for systemic change. Currently, people with intellectual and developmental disabilities are learning "on-the-job" when they are hired into research roles; however, we hope that this learning series can provide training and open new and different opportunities to join inclusive research teams.

However, we also believe that other steps need to be taken to create opportunities for employment and career development in inclusive research as described in the Network section. This is the purpose of our network of researchers and policy makers. We hope we can create a "hub" where opportunities can be shared, and matching can occur between emerging researchers and research groups and organizations. Creating a system for 'matching' emerging researchers with lived experiences with members of our inclusive research network can be expanded and replicated to create career pathways and advance equitable access to opportunities to engage in the process of research. We hypothesize this will advance the quality and impact of research because it will be collaboratively developed and shaped by people with a range of expertise and knowledge of disability and disability research. Further it is known from inclusive research that building long-term relationships and collaborations are essential to success (Bigby & Frawley, 2010). We hope that the Network can continue to grow and create opportunities for relationships development and an expansion of collaboration, trust, and inclusive relationship building.

Future Directions

Inclusive research is expanding and being more widely acknowledged and advocated for, with the overarching goal that research in intellectual and developmental disabilities is conducted by research teams that include people with lived experience with intellectual and developmental disabilities. However, more needs to be done for inclusive research to become the status quo. First, similarly to how emerging researchers with intellectual and developmental disabilities are engaging in a learning series on inclusive research in our work, there is a need for university faculty and staff and others to have training on inclusive research. Often, inclusive research is an afterthought at universities, and faculty, staff, and institutional units (e.g., research institutional review boards review boards [IRBs]) need to establish knowledge base to advance inclusive research and promote access to this knowledge base across people with and without lived experience with disabilities. Universities engaging in disability-related research should prioritize training on the importance of inclusive research and the different ways in which to center the expertise of individuals with intellectual and developmental disabilities and break down systemic barriers. Ideally, these trainings would be led or co-led by researchers with disabilities to further reinforce the importance of inclusive research and provide lived examples of supports and barriers encountered by researchers with disabilities.

Second, organizations that fund disability-related research should incorporate the expectation for inclusive research principles within their grant mechanisms. Although we are seeing some funding organizations start to prioritize inclusive research models, it is still emerging. Relatedly, universities should embed training on inclusive research into their training programs and explore ways to remove systemic barriers that maintain ableist practices (Dolmage, 2017). Third, inclusive research networks such as the one described in this article, need to become commonplace and expanded to involve the various research groups across the world that are engaged in related efforts to advance inclusive research and training. Within this expansion, more opportunities to ‘match’ researchers with lived experiences to research projects would help break down barriers to accessing research projects, particularly for marginalized groups that are often not included in the dissemination and design of research opportunities. Technology supports and the adoption of plain language will be critical.

Fourth, a focus on inclusive research can advance equity and promote shared power. By making the division of power more equitable, the current system can be changed and challenged, reducing and eliminating hiring and compensation barriers. Exploring issues of intersectionality and centering those who are multiply marginalized in rebuilding systems and practices will be critical. And finally, there must be follow-through to document the impacts of inclusive research and efforts to advance inclusive research practices. Researchers and universities can partner with disability organizations and advocacy groups to evaluate outcomes and document the impact of inclusive research projects on outcomes for people with intellectual and developmental disabilities and the adoption of research findings in policy and practice.

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Table 1

Definition and Principles of Inclusive Research

Shared Definition of Inclusive Research

Inclusive research centers the voices, experiences, and expertise of people with intellectual and developmental disabilities through all phases of research (i.e., planning, conducting, disseminating) advancing self-determination and actionable outcomes valued by the intellectual and developmental disabilities community.

Principles

- People with intellectual disability have the right to participate in all parts of the research process (planning, conducting, disseminating), aligned with their interests, preferences, and strengths.
- Inclusive research combines the skills, experiences, and perspectives of researchers with and without disabilities to generate new approaches and new knowledge that could not be generated by either group alone.
- Inclusive research is collaborative, reciprocal, and leads to actionable outcomes.
- Inclusive research involves power being shared by academic researchers and people with lived experiences and breaks down hierarchies with both groups being able to exert control at all stages of research.
- Inclusive research reflects anti-ableist values, policies, and practices.

Inclusive Research Network Vision and Mission

Vision Statement

Through inclusive research practices, researchers with lived disability experience are equal partners on every research team.

Mission Statement

Empowering researchers with and without lived disability experience to adopt inclusive research principles by:

- Creating and sharing resources to build inclusive research awareness,
- Advancing connections among researchers with and without lived disability experience and the disability community, and
- Providing an ongoing supportive community for inclusive research teams.

Table 2

Inclusive Research Learning Series Outline

Session	Topic
Introduction	
Pre-Session A	Individual Tech Check: 1:1 meetings to ensure technology supports are in place
Pre-Session B	Group introduction to the learning series; initial team building; pre-series data collection
Module 1: Basic Overview of Inclusive Research and the World Café **Research Topics:** Research (Planning, Conducting, and Disseminating), ethical and inclusive research	
1	**Learning Objectives:** Emerging researchers can define research, inclusive research, and ethical research. Emerging researchers can apply the principles of inclusive research to future research goals. Emerging researchers can list the three stages of the research process. What is research? What is inclusive health research and why is it important? • Defining research • Defining inclusive research • Three states of the research process: Planning, Conducting, Disseminating
2	**Learning Objectives:** Emerging researchers can list research skills and identify their strengths. Emerging researchers can summarize research ethics. Emerging researchers can describe the format and process of a World Café. What is ethical research? What is the World Café and how will it build our research skills? • Overview of research skills: Asking research questions, Sharing experiences. Talking to other people, Coming up with ideas, Planning, Implementing a plan, Identifying solutions, Being a leader • Defining research ethics • Why are research ethics important? • Examples of research ethics in action • How will we use our research skills in the World Café? Developing research questions, Recruiting participants, Collecting data, Analyzing data, Sharing findings with others
Module 2: Planning and Designing a Research Project/World Café **Research Topics:** Planning and designing a study (research questions, participants, and timeline)	
3	**Learning Objectives:** Emerging researchers can explain the role of research questions and participants in the research process. Emerging researchers can identify potential topics for their research project and explain key considerations in research study timeline development. Emerging researchers can identify strategies to implement inclusive practices during the process of research question development, identifying participants, and determining research timelines. What do you consider when planning and designing a study? • Research questions (What do you want to know?) • Participants (Who has the answers?) • Timeline • What are the different forms of inclusive engagement?
4	**Learning Objectives**: Emerging researchers can create research questions for a topic of interest.

	Emerging researchers can identify participants for a question of interest. Emerging researchers can identify considerations when creating a timeline for a research project. What questions will we address with our World Café and who do we want to invite? • World Café Principle: Explore Questions that Matter • World Café Principle: Set the Context • World Café Principle: Connect Diverse Perspectives
Module 3: Conducting a Research Project and World Café Part I **Research Topics:** Conducting a study, participant recruitment, data (qualitative and quantitative)	
5	**Learning Objectives:** Emerging researchers can define hypothesis and identify hypotheses for their World Café research questions. Emerging researchers can define participant recruitment and identify key practices in the ethics of recruiting participants. Emerging researchers can define data collection. What do you consider when conducting a study? • Participant recruitment - How can we get the right people? • Data - What is the best way to learn what we need to know? Qualitative research, Quantitative research • Different forms of inclusive engagement in this phase
6	**Learning Objectives**: Emerging researchers can explain the difference between quantitative data and qualitative data. Emerging researchers can define data and name different strategies for data collection. Emerging researchers can plan ways to gather meaningful data from World Café participants to answer the research questions. How will we recruit and what data will we collect? • Identify recruitment ideas and action steps • Develop the World Café draft What kind of data do we need?, What challenges might come up?, What solutions or strategies might help to address these challenges?
Module 4: Conducting a Research Project and World Café Part II **Research Topics:** Research Engagement	
7	**Learning Objectives:** Emerging researchers can identify at least two strategies for promoting accessible, equitable, and ethical participant engagement during research. Emerging researchers can apply strategies for promoting accessible, equitable, and ethical participant engagement to their World Café planning. Emerging researchers can identify potential barriers and associated solutions to participants' access and engagement during the World Café. What do you consider when engaging people with and without disabilities in a study? • How people should feel during research • World Café Principle: Create a Hospitable Space • World Café Principle: Encourage Everyone's Contribution
8	**Learning Objectives:** Emerging researchers can recall and explain how to implement World Café design principles and can identify the roles and their associated responsibilities. How do we want people to feel/engage during our World Café?
World Café Event	
9	**Learning Objective:** Emerging researchers can plan to host a World Café. Prepare for the World Café: finalize breakout groups and roles.
10	**Learning Objective:** Emerging researchers can plan to host a World Café.

	Prepare for the World Café: practice facilitation.
11	**Learning Objective:** Emerging researchers can conduct a World Café in accordance with the World Café design principles. Host the World Café.
Module 5: Analyzing a Research Project and World Café Data **Research topics:** Analysis of qualitative data, analysis of quantitative data	
12	**Learning Objectives:** Emerging researchers can describe one method for analyzing qualitative data. Emerging researchers can describe one method for analyzing quantitative data. Emerging researchers can describe two ways to visually represent data. What do you consider when analyzing a study? • What is the best analysis approach? • What information do we want to be able to share? • What expertise is needed? • Who has the skills to support the process and who should be involved? • What are the different forms of inclusive engagement in this phase?
13	**Learning Objectives:** Emerging researchers can develop an analysis plan for the data collected during the World Café. How will we analyze our World Café data? • World Café Principle: Listen Together for Patterns and Insights • Develop an analysis approach. • What challenges might come up? • What solutions or strategies might help to address these challenges?
Module 6: Disseminating a Research Project, World Café Findings, and Future Action **Research Topics:** Disseminating research findings from qualitative and quantitative data	
14	**Learning Objectives:** Emerging researchers can interpret and represent the data from the World Café. Emerging researchers can describe key considerations for disseminating research findings including who needs the information, how to reach the chosen audience, and accessibility of data. What do you consider when disseminating a study? • What is the best dissemination approach? • Who needs this information? • What is the best way to reach them? • How do we know our data are accessible?
15	**Learning Objectives:** Emerging researchers can develop a dissemination plan for the data collected during the World Café. Emerging researchers can disseminate the findings from the World Café. Emerging researchers can apply the principles of inclusive research to their future research goals. How will we share our World Café findings and what lies ahead? • World Café Principle: Share Collective Discoveries • How can we continue to be engaged in research? • What parts of research are we most passionate about? • How can we advocate and ensure disabled voices are heard during the research process?
Conclusion	
16	Wrap-up; Reflections; Summary of what has been learned; post-series data collection.