Intellectual and Developmental Disabilities

Research About Us, With Us: An Inclusive Research Case Study
--Manuscript Draft--

Manuscript Number:	IDD-D-23-00022R1
Article Type:	Research
Keywords:	intellectual disability; developmental disabilities; inclusive research; community-based research
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Abstract:	Inclusive research combines the expertise of academically trained researchers with the lived experience of individuals with disabilities to render results that are more accessible, accountable, and meaningful to the disability community. In this case study, adults with intellectual and developmental disabilities (IDD) contributed as co-researchers to a series of studies on mental health of adults with intellectual disability. The research model, specific engagement strategies, and lessons learned are shared. Feedback from members of the research team suggests that including adults with IDD as co-researchers benefited investigators, co-researchers with IDD, and project outcomes. Our case study emphasizes the valuable contributions of research partners with IDD and provides a model that may be adapted and utilized by researchers to enhance their practice.

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Abstract

Inclusive research combines the expertise of academically trained researchers with the lived experience of individuals with disabilities to render results that are more accessible, accountable, and meaningful to the disability community. In this case study, adults with intellectual and developmental disabilities (IDD) contributed as co-researchers to a series of studies on mental health of adults with intellectual disability. The research model, specific engagement strategies, and lessons learned are shared. Feedback from members of the research team suggests that including adults with IDD as co-researchers benefited investigators, co-researchers with IDD, and project outcomes. Our case study emphasizes the valuable contributions of research partners with IDD and provides a model that may be adapted and utilized by researchers to enhance their practice.

Research About Us, With Us: An Inclusive Research Case Study

Inclusive research that engages individuals with lived disability experience as study partners is a vital application of the disability rights motto: "nothing about us, without us." While defined variously (e.g., Chalachanova et al, 2021; O'Brien et al, 2022; Walsmsley et al., 2018), inclusive research combines the lived expertise of individuals with intellectual and developmental disabilities (IDD) with the research expertise of academically-trained researchers to render findings that are more accessible, accountable, and meaningful to the disability community (Walmsley, 2001). Engaging community stakeholders on the research team is recognized as essential to high-quality social and health science research (Di Lorito et al., 2017; O'Brien et al., 2022). Various formats of inclusive research are described in the extant literature, including use of narrative method (Chalachanova et al., 2021); shadowing (e.g., Van der Weele et al., 2021); and co-research (e.g., Di Lorito et al., 2017). In this paper, we present our inclusive research experience as a case study, sharing strategies and the impact of engaging adults with IDD as part of our research team.

Benefits of Engaging Adults with IDD in Research

Inclusion Strengthens Research

Research partners with lived disability experience can inform and strengthen all stages of the research process from identifying research questions that are meaningful to the disability community to effective dissemination of key study findings (Walmsley et al., 2018). Including co-researchers with disabilities increases the diversity of perspectives, identifies the research topics of most relevance to people with IDD, and amplifies the invaluable insight of individuals with lived experience (Walton et al., 2022). Co-researchers with disabilities lend credibility to the research when recruiting participants with disabilities (Di Lorito et al., 2017); provide a

deeper understanding to the interpretation of data (Chapman, 2014); and facilitate the dissemination of clear and accessible findings that can be understood and utilized by stakeholders (O'Brien et al., 2022). This is fundamental to fulfilling the citizenship and right to knowledge of benefit to the IDD community (Chalachanova et al, 2021).

Inclusive research requires development of competencies by both academic co-researchers and co-researchers with IDD. Embregts et al. (2018) identified the competencies required as including the capacity to build mutual relationships, communication, collaboration in which everyone can contribute, being aware of each other's skills and developmental needs, and being aware of how context can impact co-researchers. Recent research has also discussed differences in the roles of co-researchers with and without IDD, each contributing from their areas of strength and expertise (Frankena et al., 2019).

Inclusion Benefits Researchers

In addition to improving the quality of IDD research, adults with IDD benefit directly from their co-research role. Co-researchers with disabilities reported feeling a sense of empowerment by being a role model and advocate for the community (Butler et al., 2012; Williams & Simons, 2005); a sense of pride and accomplishment in having one's voice heard in a professional setting (Kramer et al., 2011; Williams & Simons, 2005); and an increase in professional and pragmatic skills through meaningful occupation (Conder et al., 2011; St. John et al., 2018). They have reported expanded social and support networks (Grayson et al., 2013) and a sense of belonging from research engagement (Riches et al., 2020; St. John et al., 2018). Co-researchers with IDD indicated that involvement in the process increased their interest to engage in additional research activities (McDonald et al., 2013; St. John et al., 2018).

Inclusion provides co-researchers without disabilities opportunities for professional collaboration, mutual learning, and reciprocity (Nind & Vinha, 2014; Riches et al., 2020), which promotes understanding and positively changes individual beliefs about adults with IDD (McDonald et al., 2017). After practicing inclusive research, co-researchers without disabilities reported that their assumptions were challenged, and they had increased expectations and more positive attitudes about what co-researchers with disabilities could contribute (Butler et al., 2012; Chapman, 2014).

Barriers to Inclusive Research

Individuals with disabilities continue to be excluded from research participation due to concerns about vulnerability to informed consent and coercion (Di Lorito et al., 2017; McDonald & Raymaker, 2013). Although research ethics standards and practices have evolved, attitudes among researchers, human subjects review boards, and the disability community itself continue to discourage research engagement among adults with IDD (O'Brien et al, 2022). While historical exploitation has led to a distrust of research, McDonald et al. (2017) note that many individuals with disabilities find exclusion from research as overtly harmful. This reinforces the value, credibility, and need for ethical inclusive research.

Individuals with IDD continue to experience discrimination that prevents them from participating in research as participants and as partners. Human subjects protection (2009) federal code requires that Institutional Review Boards give special consideration to protecting potentially vulnerable subjects, which includes individuals with mental disabilities or cognitive impairments. Individuals with ID may be considered vulnerable because of concerns that they may have difficulty comprehending information and making decisions, such as providing informed consent to participate in research (Gordon, 2020). This categorical approach assumes

that the whole population may be easily manipulated or coerced during the research process and does not consider individual variations in the degree of vulnerability (Gordon, 2020). While research participants, including participants with disabilities, may consider incentives to be a direct benefit of research, IRB members and others in the research ethics community worry that incentives could be coercive for "vulnerable" groups (McDonald et al., 2017). These assumptions promote a deficits-based mind-set that dismisses the capacities and interests of individuals with IDD, if provided with supports, while discouraging researchers from designing studies that directly engage members of the population.

Additional barriers to inclusive research are related to financial and university system issues. Equitable compensation to co-researchers with disabilities may be limited by disability benefit eligibility requirements in the United States. As of this writing, adults with disabilities risk losing social security disability income and health insurance benefits if their average earnings exceed $1,470 per month (Social Security Administration, 2023). In order to protect human subjects, members of the research team are required to complete human subjects training before assuming research roles, such as recruiting participants, collecting data, and interpreting findings. These required trainings are costly for researchers who don't have a university affiliation and require a high level of receptive language and literacy (Hadden et al., 2018).

Researchers face many challenges in the engagement of individuals with IDD as equal partners in the process of designing and implementing studies. Communication and comprehension limitations associated with IDD may pose barriers to equitable research engagement (McDonald & Raymaker, 2013). The academic and technical process of rigorous research is complex and incremental, which can be discouraging for co-researchers with IDD and others unfamiliar with the research process. While a recent review of literature revealed over 50

studies between 2006 – 2016 that included partners with ID, "only four studies took an approach where self-advocates were leading and controlling" the purpose and aim of the research endeavor while the majority (n=41) represented a collaborative group approach led by academic researchers with dispersed control among team members (Jones et al., 2020, p.113). Good planning and deliberate use of effective strategies are required to address and overcome these common barriers to inclusion and full involvement of co-researchers with IDD (Di Lorito et al., 2017).

Strategies for Inclusive Research Practice

Personalized supports may be needed to fully engage adults with IDD due to limitations associated with these disabilities in areas such as communication, problem solving, literacy, and self-direction (Schalock et al., 2021). Communication preferences, unique strengths, and specific needs may be assessed to inform the development of individualized support strategies. Specific accommodations might include the use of assistive technology or a communication device, modified or multi-modal meeting materials, and a study partner or support person who knows the person well. A partner may be especially helpful to support mutual understanding between team members due to linguistic diversity or to support participation during virtual meetings. Importantly, professionals should use plain language, or clear, concise, and well-organized communication, to make information more accessible and comprehensible to all team members (Plain Language Action and Information Network, 2023). It is imperative that we uphold the human and legal rights of individuals with IDD for full participation, equal opportunity, independent living, and economic self-sufficiency by having high expectations and providing supports that empower the unique value, strengths, and abilities of this population (Americans with Disabilities Act, 1990; Chapman, 2019).

The following five strategies have been identified as key to successful inclusive research (Butler et al., 2012; Nicolaidis et al., 2019; Strnadova et al., 2014): (1) Build trust and solidify shared goals with community partners; (2) Be transparent about the goals of including community partners with IDD in the research; (3) Clearly define community partner roles and expectations while providing training, as needed; (4) Create processes for effective communication and power sharing while providing accommodations, as needed; and (5) Collaborate to share clear and accessible research findings with stakeholder audiences. By engaging these strategies, the voice of members who belong to the population being examined are empowered to shape research agendas, determine project priorities, and guide decision-making based on community-identified needs and actions (McDonald & Raymaker, 2013).

Purpose

The purpose of this paper is to describe an examination of our inclusive research activities as a case study. This study contributes to previous research by addressing two questions: (1) How does partnering with adults with IDD as co-researchers impact IDD research?; (2) What impact does inclusive research have on IDD researchers and co-researchers with IDD? We present specific examples of our practice and describe the impact of our practice on project outcomes and on research partners with and without IDD.

Method

In 2018, our research team successfully responded to a funding opportunity with a short time-to-submission to establish a five-year Rehabilitation Research and Training Center (RRTC) on the health and function of adults with ID and mental health concerns. We proposed conducting three studies designed to: (1) develop and test cognitively accessible measures of health, mental health, and health-related quality of life; (2) examine the prevalence rate of mental

health conditions in adults with ID; and (3) generate guidelines for effective psychotherapy for adults with ID. Our research structure was built on a Learning Collaborative model with two interconnected expert panels that guided project decisions and collaborated on research activities: (1) the Research Experience Expert Panel [REEP]; and (2) the Disability Experience Expert Panel [DEEP]. The project's Principal Investigator (PI) and a co-Investigator with lived developmental disability experience served on both the REEP and DEEP to coordinate efforts between the two panels.

Participants

REEP and DEEP members served as paid consultants for the project, as well as participants for this case study. Demographic information was never explicitly requested from co-researchers, but some information about their diversity is known from self-disclosure. The REEP is composed of twelve nationally renowned researchers with expertise in IDD, health, technology, and self-advocacy. The REEP includes members with and without disabilities, including individuals with attention-deficit/hyperactivity disorder and lived experience of cerebral palsy. This team met monthly to discuss issues related to advancing the project's goals. Twelve adults with IDD, who had prior training and experience with advocacy and an interest in mental health, were recruited to form the DEEP. Specifically, several members had completed Project STIR (i.e., Steps Toward Independence and Responsibility) training, a program designed to provide individuals with tools to advocate for themselves, work with others in advocacy, and gain leadership experience (Ohio Self Determination Association, 2023). The group is comprised of adults with lived IDD experience, including co-occurring mental health conditions. The DEEP is co-chaired by two staff members with lived disability experience. DEEP engagement was supported by a DEEP leadership team, comprised of the PI, research staff, and DEEP co-chairs.

Procedure: Inclusive Research Practice

We used the following strategies to engage DEEP members as co-researchers:

1. Built Trust and Maintained a Shared Vision

Building trust was prioritized from the first meeting, in order to create a safe and comfortable working environment for all team members to express themselves openly. The DEEP met regularly to establish an understanding of the research project and to foster camaraderie. Meetings were held in-person on a quarterly basis prior to COVID-19 and bi-monthly via video conference during the lockdown. Rapport building activities were regular meeting components to develop relationships within the DEEP and leadership team. For example, "ice breakers" (e.g., discussion prompts) were used to encourage socialization and help team members learn more about each other. During one meeting, team members were asked to provide a favorite song, and staff members created a playlist that was played during meeting breaks. In general, meetings would begin and end with informal discussions that encouraged friendly conversations where team members had an opportunity to share fun or interesting news from their personal lives. Providing meeting agendas and materials a week in advance allowed time for information processing to promote active engagement during group discussions.

A key role for DEEP members was to offer their opinions and feedback to academic co-researchers on engaging adults with ID in mental health research. In order for the research to benefit from their lived experience, they needed to speak up when a suggested item or particular word was unclear or insultingly childish. While many DEEP members had prior advocacy training, the DEEP Leadership team engaged in self-advocacy exercises and role-play scenarios to build confidence and capacity to ask questions and express opinions in the research context.

During meetings, speaking up and sharing ideas was regularly emphasized as a critical and valued component of their role on the project.

The team worked together to develop a common understanding of the research process and goal. As DEEP members had not previously contributed to research as participants nor as co-researchers, we regularly discussed similarities and differences between research and advocacy. Borrowing from the Research Engagement and Advocacy for Diverse Individuals project (READI; Ausderau & Health Research Engagement Development Team, n.d.), the following three main stages of research were defined: (1) asking questions; (2) finding answers; and (3) sharing what we learn. The team discussed each stage in relation to our project. For instance: (1) we wanted to know how many adults with ID have mental health concerns; (2) we asked adults with ID about their health; and (3) we shared our findings through published articles and clear language translations, presented webinars and conference sessions, and made social media posts. Team meetings were supported by presentation slides with visual supports, videos, activities, and worksheets to support multi-modal learning and engagement. One tool leveraged the study's slogan, "HEAR ME," as an acrostic aid to outline key aspects of the project's purpose and goals, which was reviewed at the beginning of meetings.

2. Established Transparent Partnership Goals

The first partnership goal for DEEP members was to be fully engaged as co-researchers in the adaptation of existing health assessments, in order to modify a cognitively accessible measure for adults with ID. Their expertise and input were crucial for improving clarity and accessibility. Within the first year of the partnership, their contributions expanded to discussions on participant recruitment strategies, including compensation rates, and knowledge translation and dissemination activities.

Early in the project, we held an orientation meeting with all research team members to explain the research goals, project activities, and structure of the Learning Collaborative. This in-person meeting served to build community amongst the three core teams: the investigators and project staff, the REEP, and the DEEP. In addition to building trust and rapport, part of this orientation day was devoted to engaging DEEP members in discussions about their role and expectations on the study and assessing their communication preferences and support needs to inform individualized accommodations.

Providing needed accommodations to effectively support participation was key to creating a respectful working relationship and collegial culture. An initial assessment given to DEEP members revealed that about half of the members preferred learning new information by reading written text while the other half preferred learning through audio-visual modes. One member disclosed that they did not read and needed to learn information through multimedia, text-to-speech software, or discussions. Another member noted that they needed others to be patient with them, so that they had enough time to think and respond without interruption. Other members revealed a need for meeting materials with larger font size, as well as to receive materials at least one-week in advance to review and prepare for meetings. The assessment provided necessary information to tailor individualized support plans and guide multimodal instruction during group meetings to review project goals and expectations.

3. Clearly Defined Roles

Annual consultant agreements with DEEP members clearly outlined their responsibilities and expectations. For example, they were expected to: (1) attend an annual summit meeting with investigators and the REEP; (2) attend regularly scheduled meetings with other DEEP members

and project staff; and (3) provide input during and between meetings. DEEP members were expected to review meeting materials and come prepared to discuss their ideas.

Expectations for professional communication were established through training sessions and clearly restated at the beginning of each meeting by a DEEP co-chair. For instance, each meeting would begin with a reminder about the team's best practices for effectively contributing to our research meetings, such as: (1) share your ideas with others but take turns and do not interrupt others; (2) raise your hand to indicate that you have something to share and wait to be called on; (3) attentively listen to others while they are speaking; (4) use active listening skills to clarify or emphasize what someone else has said; (5) stay muted in virtual meetings, except when speaking, to avoid background noise; (6) feel free to use the chat feature in virtual meetings to share ideas or ask questions. Regular meetings provided ample opportunity to remind the co-researchers about their valued role as advisors and collaborators.

Lastly, the PI and a DEEP co-chair conducted annual performance review meetings with each member to discuss their work on the project. A rubric was used to reinforce roles while considering contributions aligned with meeting attendance and active engagement.

4. Created a Process for Effective Communication and Power Sharing

During an initial training session, self-assessments were conducted to learn about each DEEP member's communication preferences and individual support needs. This information allowed the research team to better understand how to work with each individual, adapt and modify meeting materials, support multimodal learning, and promote options for active engagement and meaningful participation. Several strategies for effective communication were tried and refined. Important practices that supported research partners with IDD included the use of plain language (Plain Language Action and Information Network, 2023) and Universal

Design for Learning (UDL) guidelines (CAST, 2018). Some members utilized assistive technology (i.e., text-to-speech) to participate in activities (e.g., website review), and a few co-researchers with IDD attended meetings with support staff, who helped to facilitate interaction and comprehension.

      Adapting Health Measures. The project's education specialist, who facilitated DEEP engagement in research activities, prepared worksheets and presentation slides to guide each training session and meeting. For example, when translating health measures into cognitively accessible language, items with high level vocabulary or abstract concepts were listed on a worksheet together with alternate phrasing. Worksheets used 16-point font and were limited to 1- or 2-items per page. During an in-person project meeting, the education specialist provided copies of the worksheet to each member and shared the file through a projector system. Each original item was read aloud, followed by modified options for how to rephrase the item. DEEP members were asked to identify their preferred option by circling or underlining it on their printed worksheet. They were also invited to share ideas for other ways to present items or express difficult constructs. Group discussions and polling were used to reach consensus.

      Selecting Response Options and Illustrations. To support the written questions, we asked DEEP members to select images that clearly illustrated key ideas. The education specialist used a projector to present choices on a large screen. DEEP members were shown a sample question and response options (i.e., almost never, sometimes, and almost always). Each slide included a sample statement (e.g., *In the last two weeks, I had trouble sleeping*), and a photograph (e.g., a person lying awake in bed). Slides presented the response choices alongside different sets of images (i.e., cylinders with varying levels of fullness, pie charts, and different

calendar options). A final slide included all of the different options and the following questions:
(1) Which pictures did you like best?; and (2) Do you have other ideas that would be better?

The group voted on the preferred option by raising hands. Then, the group discussed their choices and suggested other ways to illustrate the concept. Quick follow-up polls were used to see whether preferences changed following the discussion. Tallies and discussion notes were recorded and provided to the investigator team.

Power Sharing. DEEP members actively engaged in the research process and influenced important research decisions. In adapting research measures, for example, the DEEP strongly preferred rating scales with three, as opposed to four, response options. Believing that four response options was best practice, investigators agreed to the three-point scale with reservations about sensitivity. Pilot studies found that item variance was not a problem (Walton et al., 2022). As another example, investigators wanted to ensure that every participant had the opportunity to speak for themself without needlessly burdening participants with a barrage of questions that they could not answer. In the process of developing guidance to determine whether or not participants could provide self-report, the DEEP members reminded investigators that individuals with ID can learn to respond to research questions with practice and individualized supports. This discussion led to the development of a learning module to teach participants about the response options and how to respond to the survey, which became part of our protocol.

5. Collaborated to Disseminate Findings

DEEP members actively contributed to dissemination efforts, presenting research findings at local and national conferences and webinars. In addition, the DEEP developed a clear language summary for each published research paper to ensure that our findings were accessible to a broad range of stakeholders. We use the term "clear language" instead of "easy read" or

"plain language" because the DEEP considered it less childish and more easily understood. We applied UDL strategies to increase accessibility and comprehension of technical terms and concepts. Strategies included using large font [i.e., 14+ point], short sentences, common words, easy-to-follow design features to organize information, and visual supports. We also used accessibility features, such as Word text styles and alt text to describe images to make products accessible to assistive technology. Clear language products included one-two page briefs, four-six page summaries, and ten or more page documents.

A knowledge translation (KT) process to translate scientific papers into clear language summaries was developed by a KT committee, composed of the education specialist and a co-Investigator, who was a member of the research staff with dissemination expertise. As shown in Figure 1, the KT committee engaged authors of the scientific publication and members of the REEP and the DEEP across the process.

<Insert Figure 1>

First, our KT committee worked with the publication authors to decide the main audience for the translation and the type of clear language product to make. While most of our products are intended for adults with disabilities and their families, we also made products for mental health providers. Second, the authors summarized the research questions, main findings, and implications using a KT table that was created for this purpose. In the third step, the authors presented the main points of the paper to the DEEP, and the KT committee engaged them in a guided discussion with presentation slides to identify words and ideas that were not clear, answer questions, and ask for recommendations to improve the product. Based on the discussion, the KT committee drafted a clear language product and collaborated with the DEEP and authors to update the draft by revising text, replacing illustrations, or reorganizing information. Finally,

members of the DEEP presented the clear language product to the authors to ensure that it accurately translated the original article. After final revisions were made by the KT committee, the product was shared on the project website, social media channels, and personal and professional networks. All members of the research team supported dissemination.

Inclusive Research with the Disability Experience Expert Panel

An educational specialist assumed primary responsibility for coordinating and providing support for DEEP engagement. He was supported at 50% FTE on the project for the first three years and 20% in years four and five. In the first few years, another staff member supported administrative tasks, such as setting-up and processing consultant agreements, but these tasks were later transferred to the educational specialist. Collaborating with the PI, REEP-DEEP liaison, and the DEEP co-Chairs, the educational specialist developed meeting agendas and materials to facilitate regular DEEP meetings. The DEEP leadership team held monthly, 60–90-minute planning meetings. Prior to the COVID-19 pandemic, quarterly, in-person, full- or half-day meetings were scheduled in a conference room. During the pandemic, bi-monthly, virtual, 90-minute meetings were held through video conference software. In between meetings, the educational specialist engaged DEEP members through requests for input or feedback via email, phone, or online surveys. The educational specialist reported DEEP activities and input to the REEP during monthly, 60-minute meetings. Finally, the educational specialist led the project's KT process by collaborating with REEP authors and DEEP members through email communications and meetings to gather input, draft and revise clear language products (i.e., translations of academic articles), and publish finalized products on the project website.

The team worked together to develop a common understanding of the research project and process. Addressing misperceptions and identifying key differences between participation in

health research (e.g., providing information about health to researchers) and self-advocacy in healthcare settings (e.g., talking to doctors about health) was an on-going effort. Effective communication strategies were employed to reinforce goals, review responsibilities, and practice teamwork. A respectful and inclusive team culture was established at the onset to share power and preserved through rapport building exercises that encouraged engagement.

By the end of the project, the DEEP had contributed to many phases of the research process, including: (1) participant recruitment; (2) development of research measures; (3) data interpretation; and (4) knowledge translation and dissemination of findings to IDD stakeholders.

Evaluation: Assessing the Impact of Our Inclusive Research Process

At the end of each project year, we sought feedback from DEEP and REEP members about their experience on the project to regularly assess and improve our research practice. We asked members about the project's impact on their personal and professional development, as well as their perspectives on how the DEEP impacted the overall project. For the purpose of this case study, the authors extracted and examined survey data records previously collected and securely stored within an internal project database. The data included survey responses from DEEP members gathered at the end of project year three and survey responses from REEP members gathered at the end of project year four. Twelve DEEP members and seven REEP members responded to the surveys. The author group independently reviewed survey responses and then worked together to identify exemplary quotes, interpret key findings, and summarize the results of each panel's survey. We used our findings from this process evaluation to answer the following questions: (1) How did partnering with adults with IDD as co-researchers impact our research project? (2) What impact did inclusive research have on our investigators and co-researchers with IDD?

Results

Summary of DEEP Feedback

Impact of Stakeholder Engagement on the Research

Most DEEP members indicated that their voice and ideas were included and valued a lot by the research team [11/12]. Ten DEEP members agreed that they helped the research team: (1) explain ideas in clear language; and (2) make important project decisions a lot of the time. Collectively, they emphasized the benefit of their engagement on the project as supporting the research team with their input, which brought the knowledge of lived experience to the table.

DEEP members' perceptions about their positive impact on the research project was highlighted by the actual effect that it had on critical decisions taken by research team members. For example, during early stages of the measurement adaptations study, DEEP members advised REEP members to adjust the four-point Likert response scale to a three-point scale. Although hesitant of how this might affect the instrument's sensitivity, the researchers ultimately decided to move forward with the DEEP's recommendation based on their lived experience and emphatic view that it was needed to reduce the cognitive load on users. DEEP members also influenced the design of recruitment materials, including the development of informational videos, the use of preferred language in articles and clear language products (i.e., individuals versus people with disabilities), and an increased amount of compensation offered to research participants for their effort and time spent responding to our measures and completing the research protocol.

Impact of Stakeholder Engagement on DEEP Members

All twelve respondents reported that being a DEEP member improved their self-advocacy and communication skills a lot. A majority indicated that they learned about the importance of including individuals with disabilities in health research [11/12] and learned more about health

and health research [10/12]. When asked, "*what have you enjoyed most about being a DEEP member?,*" themes emerged related to advocacy, inclusion, networking, and personal development. One member stated, "*the fact that I get to have input into something so important such as health research*." Others said, "*being able to contribute my ideas [in] a business meeting;*" "*I enjoy getting listened to and my feeling important;*" and, "*being able to be [an] advocate and learning about the health care field within disabilities*." Members also mentioned "*the friendships and business-related relationships I have made;*" "*making new friends and learning all this;*" "*seeing [and] talking to people;*" "*learning new things and meeting new people;*" and, "*getting to learn new people [and] come up with better research*." Eight members indicated that they would engage in another research project as a partner after their experience as a DEEP member because they enjoyed learning new things, helping people, giving their ideas, making money, and "*being a voice for [the] voiceless*."

Summary of REEP feedback

Impact of Stakeholder Engagement on the Research

According to the REEP, the inclusion of co-researchers with IDD had a positive impact on the research. All seven members identified knowledge translation as the area of greatest impact. Importantly, DEEP and REEP members' perspectives aligned on the value of including adults with IDD as co-researchers, especially related to making information and findings clear and accessible for a broad audience. Furthermore, the researchers reported that the DEEP contributed to important project decisions. One researcher reported, "*I think a lot of the work of the DEEP has impacted the overall project […] I think steps have been taken to ensure more participation and voice of people with lived experiences*."

Impact of Inclusive Research on REEP Members

REEP members reported that engaging in this inclusive research contributed to their professional development. Most indicated that they would be very likely to include individuals with IDD on research teams in the future. One researcher commented, "*We have an engaged and well-supported group who feel comfortable sharing their experiences and thoughts. They [DEEP members] have helped to ensure I am structuring my research in an accessible way and that the results can also be accessible to a wide audience. Bringing the DEEP and REEP together and watching the DEEP work was impactful for me.*"

Finally, REEP members were asked for suggestions to increase the effectiveness of our inclusive research project. Most of the responses related to increasing communication between DEEP and REEP members. For instance, the suggestion was made to host bi-annual or quarterly meetings with all team members, rather than a single annual summit and intermittent small group meetings with specific author groups. Further, they would like DEEP engagement during development of future project proposals.

Discussion

This paper contributes to the inclusive research literature by describing our experience of conducting inclusive research with adults with IDD as co-researchers across a series of studies on mental health and ID. We presented our learning collaborative model, specific strategies that were implemented in alignment with best practice guidelines (Nicolaidis et al., 2019), and findings from our process evaluation. Our findings suggested that stakeholder engagement had a positive impact on the research process and contributed to the professional development of both research professionals and co-researchers with IDD. The input of co-researchers with IDD impacted research decisions on how to recruit and incentivize research participants, phrase survey questions, frame response options, interpret initial findings, and translate research

findings into formats usable by persons with IDD, advocates, and allies. Similar to previous findings, responses from co-researchers with IDD reported that inclusive research benefited their communication and professional skills (St. John et al., 2018), social networks (Grayson et al., 2013), and feelings of empowerment by leveraging their voice and being an advocate for the community (Butler et al., 2012; Kramer et al., 2011). Consistent with Nicolaidis et al (2019), our research team especially valued the contribution of co-researchers with IDD in knowledge translation and dissemination of our findings to IDD stakeholders.

The value that individuals with IDD bring to planning services, policy development, and research is increasingly recognized in the field. In fact, during our project period, the DEEP was approached for consultation by external agencies, including knowledge translation work from a federal agency and to review updates being made to a standardized assessment tool. The desire to gain the perspectives of adults with lived disability experience by outside organizations validates the specific expertise of DEEP members to enhance project outcomes. We hope this case study will be used as a resource to facilitate more inclusive research. Although ethical research should benefit the communities of people being studied (Walmsley, 2001), research findings are typically shared in academic journals that are behind a paywall and largely inaccessible to IDD stakeholders. Our clear language products generate more accessible summaries of research findings that are ideal for IDD stakeholders, people with low literacy, and anyone with limited time or attention. Our knowledge translation process provides an adaptable model that may be used to help research teams work directly with stakeholders to share findings with individuals and communities that may benefit the most.

Including the perspectives of co-researchers with and without developmental disabilities in the proposal development phase holds the potential to constructively impact the design of

meaningful research questions, appropriate and relevant methods, and optimal dissemination strategies. Individuals with lived experience may be able to anticipate and mitigate challenges or barriers that may not be predicted by academic researchers without lived experience. However, tight timeframes between funding announcements and application due dates are more typical, which can make it difficult to recruit relevant and experienced stakeholders to serve as co-researchers (O'Brien et al., 2022). A vital outcome of this project is the development of standing panels that can advise or lead the direction of future opportunities. Importantly, our research center leveraged the perspectives of both the DEEP and REEP in crafting our re-bid proposal to continue this research.

As a field, we need to establish funding mechanisms to support standing panels of IDD stakeholders both during and between funded projects. O'Brien et al. (2022) and Kramer et al. (2011) also note logistical limitations in achieving the full involvement of co-researchers with disabilities. Establishing optimal conditions and providing appropriate supports to include adults with IDD on research teams entails additional costs for personnel support, assistive technology, and other workplace accommodations. In fact, one of our DEEP members had to refuse compensation for their time and effort towards the end of the project period, due to concerns about losing access to disability benefits. One strategy in the US may be to provide gift card honorariums beneath the threshold of reportable income (i.e., less than $600 within a single tax year). However, it is critical that compensation be equitable with the scope of work (e.g., $25 per hour for research consultation). Alternatively, members may be able to deposit earned income directly into an ABLE (i.e., Achieving a Better Life Experience) account, which can mitigate the impact on accessing qualified disability benefits.

Strengths, Limitations, and Future Research

This study benefited from engagement with national research experts and a vibrant group of co-researchers with IDD. We contribute to this body of research by evaluating the impact of our inclusive research design on the research itself and on the personal and professional development of members of the research team. This study is somewhat unique in several ways. First, we actively sought the input of co-researchers with IDD on a series of studies, rather than on a single study. This required some flexibility on the part of DEEP members to engage with a range of research questions, methods, and issues that required translating findings across different topics. Secondly, our REEP had been constituted for their specific expertise (e.g., accessible technology, epidemiology, knowledge of state DD services) and not all were familiar with inclusive research. As noted by others (Embregts et al, 2018; Frankena et al, 2019), this required REEP members to develop new competencies.

Throughout our project, we proactively emphasized trust and building a culture conducive to effective communication and collaboration. We developed and implemented targeted training on research and self-advocacy to create and maintain a common understanding of the project's goals and the knowledge and skills required to fulfill individual roles. We assessed communication preferences and provided appropriate accommodations to encourage equitable access to information and opportunities to participate in group discussions and share individual perspectives. Ultimately, the inclusion of research partners with IDD positively impacted the personal knowledge and skills of co-researchers, encouraged the advancement of inclusive practices by researchers, and improved the translation of accessible research findings.

A limitation of this case study is that our findings are based on the experiences of one inclusive research project and may not generalize to all other research teams. In our research, we adapted health measures to be accessible to adults with ID based on input from a relatively small

number of co-researchers with lived IDD experience. It is possible that a different group of community stakeholders would have produced a somewhat different adaptation. This limitation extends to all community-engaged research. Moreover, several DEEP members were identified and recruited based on a personal and professional connection to a DEEP co-chair through a local self-advocacy training. The familiarity of these group members and their prior training and expertise may have affected outcomes compared to forming a group of strangers with little or no training background. Self-advocacy groups are critical access points to networks of individuals with disabilities that professionals may leverage to recruit inclusive research partners. It is important, though, to consider expanding research engagement opportunities to individuals with IDD who are not connected to self-advocacy groups or Developmental Disability (DD) systems, and especially those from multiply marginalized communities. Secondly, on the continuum of inclusive research, our project represents an advisory and collaborative group approach (Jones et al., 2020); co-researchers with IDD were not involved in writing the grant proposal, developing the research questions, or designing the research studies.

Future research should prioritize leadership and control over studies by individuals with IDD with support, as needed. Self-advocacy groups should be encouraged to identify and respond to funding opportunities, as well as to initiate contact with state Departments of Developmental Disabilities and local University Centers for Excellence in Developmental Disabilities and institutes of higher education to build partnerships with grant administrators and academic researchers who specialize in disability studies. Existing panels, such as the REEP and DEEP, should be consulted by other organizations that want to conduct inclusive research but do not have immediate access to a trained and experienced community group with lived experience. Furthermore, organizations conducting disability-related research should initiate, train, and

support a diverse group of stakeholders to advise their work, collaborate on group projects, or lead their research agendas and practice.

Conclusion

The results of this case study emphasize the beneficial contributions of engaging co-researchers with IDD. Including their voices in research, as participants and partners, is critical to increase the relevance, accessibility, and impact of IDD research. The meaningful engagement of stakeholders in research is crucial to informing research priorities, policies, and support planning. Including individuals with IDD as primary contributors in the research process "*is essential for respecting autonomy and ability, improving services and supports, and understanding the needs of this population*" (Walton et al., 2022, pg.11). "Nothing about us, without us" encapsulates a moral imperative and legal responsibility for nations to secure the rights of individuals with disabilities for full integration and participation across every aspect of social, economic, and political life (Americans with Disabilities Act, 1990; United Nations, 2004). The inclusion of individuals with disabilities as co-researchers in disability research is an important way to realize this potential.

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Step 1: Identify Audience(s) and Product Type(s)
- KT Committee
- Authors

Step 2: Populate and Review KT Template
- Authors
- KT Committee

Step 3: Draft, Review, and Develop Clear Language Product(s)
- KT Committee
- DEEP and REEP
- Authors

Step 4: Finalize and Publish Product(s)
- KT Committee
- DEEP and REEP
- Authors