Research to Practice

Partnering with People with Intellectual and/or Developmental Disabilities to Design and Implement Research

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Issue No. 69

Introduction

Individuals with lived experience bring a rich and essential perspective to the design and conduct of research studies. Historically, people with intellectual and/or developmental disabilities (IDD) have more often been included as research subjects rather than active contributors to the research process. Participatory Action Research (PAR) shifts this dynamic by placing research populations in the roles of both subject and co-researcher with shared responsibilities and opportunities for the production and consumption of knowledge through the whole research process (Borda, 1996). This approach reflects the disability rights principle of "nothing about us without us," which emphasizes the importance of direct involvement of people with disabilities in decisions and processes that impact their lives (Ahlers et al., 2021). Inclusive research is an expanding field within the social sciences and is increasingly recognized for its potential to produce more relevant and impactful findings that inform services, policies, and practices supporting people with IDD (Buck et al., 2024).

A co-researcher is someone with lived experience who works as an equal partner on a research team. Co-researchers help plan the study, conduct recruitment, collect and analyze data, and share findings, using their real-life knowledge to make research more relevant, accessible, and meaningful.

Research shows that including people with lived experience strengthens studies by bringing real-world perspectives that help shape research questions, improve participant recruitment, strengthen data interpretation, and increase the accessibility and usefulness of findings for intended audiences. This also adds authenticity and credibility, helping ensure that research reflects what truly matters to people with IDD (Buck et al., 2024). Despite these benefits, clear guidance on how to effectively and rigorously include individuals with IDD—using methods that are proven to be valid and reliable—remains limited, particularly for virtual research settings (Sadler, 2023). Addressing these gaps is essential to supporting meaningful participation and strengthening inclusive research practice.

This brief contributes to the growing knowledge base about inclusive research by sharing lessons learned and practical recommendations from our experience implementing a virtual qualitative research study. It is intended for researchers who seek to implement or expand inclusive research approaches in their work with individuals with IDD.

Research Project Background

The Guardianship Alternatives and Transfer-of-Rights (GATOR) project (2019–2023), led by the Institute for Community Inclusion (ICI) and funded by the Institute of Education Sciences, explored how transfer-of-rights (ToR) and guardianship discussions in special education settings impact transition outcomes for students with IDD. ToR means that at the age of majority (age 18 in most states), education rights transfer from the parent to the young adult. This project examined how these discussions were conducted in practice and their impact on parental expectations and student self-determination, with the goal of improving transition experiences and informing future interventions. The ICI partnered with Massachusetts Advocates Standing Strong (MASS) and the Self-Advocacy Association of New York State (SANYS), in consultation with staff from Harvard Law School Project on Disability (HPOD) to implement this research study.

This brief describes how researchers at the ICI and HPOD partnered with self-advocates from MASS and SANYS to implement all aspects of a GATOR research study. The team conducted qualitative interviews with students with IDD, their parents, and their special educators virtually (on Zoom) in school districts in Massachusetts and New York.

As part of that effort, four self-advocates from MASS and SANYS worked alongside researchers from ICI and HPOD. They were paid employees of their respective organizations and worked remotely. MASS and SANYS staff provided support to co-researchers as needed through a hybrid model that included both remote and in-person support as needed.

Role of Self-advocate Researchers in Study Implementation

Co-researchers from MASS and SANYS played a central role in every phase of the research, including (1) human subjects training, (2) recruitment of study participants, (3) data collection, (4) data analysis procedures, and (5) product development and dissemination. Staff from ICI were responsible for ensuring that all aspects of the research process were accessible, and multiple measures were implemented to support full and meaningful co-researcher participation at each phase, as described in the following section.

Human Subjects Training

ICI staff trained co-researchers on human subjects research principles and the importance of ensuring that research is done safely, respectfully, and in ways that protect participants' rights and well-being. To begin, co-researchers reviewed a plain language version of the Belmont report, a document that contains rules that guide how research with people should be done ethically, safely, and fairly (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Next, ICI staff led 1-hour training on Zoom to ensure co-researchers understood the principles outlined in the Belmont report and had the opportunity to ask clarifying questions. After the training, ICI held a practice session for co-researchers to practice asking interview questions while applying the lessons learned from the training on conducting human subjects research.

Recruitment of Study Participants

Co-researchers were instrumental in recruiting research participants through their professional and peer networks as well as helping ICI staff determine optimal venues for recruitment. Co-researchers and ICI staff co-developed study recruitment flyers using targeted, accessible language to describe the study and clearly explain the benefits and risks of participation.

Data Collection Procedures

Consent Procedures. Co-researchers worked to improve a consent form used in a previous project, helping to finalize an accessible version that incorporated plain language, visual cues, and icons to support student understanding. The consent form used a series of subheaders alongside each icon and concrete examples and questions. It explained the purpose of the study, what participation involves, and potential risks and benefits. It also emphasized participants' rights to ask questions, skip questions, or decline participation at any time.

To ensure the consent process was clear, student participants received the consent form in advance of their scheduled interview. Before beginning the interview, co-researchers asked whether students had any questions and, when needed, reviewed the consent form verbally, subheader by subheader, explaining key concepts. Co-researchers obtained verbal consent during the interview.

Interview protocol. Co-researchers also played an instrumental role in developing an accessible, semi-structured interview protocol. Drawing on their lived experience as former special education students, co-researchers worked with ICI staff to create plain-language questions that reflected real-life conversations with special educators. The protocol was designed to gather student perspectives on ToR, guardianship, and decision-making during the transition from high school. The opening script emphasized participant choice, informed consent, and flexibility to skip questions, take breaks, or stop the interview at any time.

Conducting online interviews. Co-researchers led, conducted, and recorded all student interviews on Zoom with support from ICI project staff. Prior to beginning, ICI staff compiled an interview preparation checklist that was reviewed and shared with co-researchers to ensure that all student interviews were implemented consistently. The checklist outlined the steps to gather informed consent, effective use of interview materials, and use of accessibility features on

Zoom (captioning and recording). The checklist also emphasized the option to practice at pre-meetings and reflect during post-interview debriefs between ICI staff and co-researchers.

After conducting several interviews, co-researchers recommended creating a visual aid to further increase accessibility for the student interviewees. They developed a PowerPoint presentation that would be screen-shared with the students while the interview questions were asked. This made it easier for the students to follow along with the questions. They also recommended further revisions to the interview protocol to improve flow and comprehension.

Data Analysis

After completing the student interviews, co-researchers then summarized, analyzed, and interpreted the student interview data. Instead of reading interview transcripts, co-researchers were assigned to watch videos of all the student interviews. As they watched each interview, they recorded answers to the following five research questions:

1. What was the student's involvement in transition planning or individual education planning (IEP) meetings like?
2. What are the student's hopes and dreams for their future?
3. What did the student remember about discussing ToR or "turning 18" at school?
4. What did the student remember about discussing ToR or "turning 18" with others?
5. What was the student's involvement in choosing guardianship or an alternative?

ICI staff compiled the answers and trained co-researchers to identify common themes or "big ideas" in the data using the guiding question: "What is common across all student interviews with respect to how they answered this question?" This exercise generated multiple themes for each research question. Several group discussions helped to further refine the themes.

Product Development and Dissemination

Based on this research, co-researchers published a brief titled Turning 18: What Parents & Teachers Need to Know, created a Turning 18 video series, and presented at multiple national conferences and webinars. ICI staff supported co-researchers to author project findings by developing outlines with multiple feedback loops during publication drafting and using scripts and detailed protocols to support collaborative presentations. Co-researchers also disseminated research findings through their professional and peer networks.

Recommendations for Researchers on Inclusive Research

Build in extra time: ICI staff often underestimated the time needed to implement the study, particularly for preparation and training. Researchers should plan for additional time and resources to review key concepts, such as the importance of consent procedures and the details of interview protocols, especially when teams are new to inclusive research. Plenty of extra time will ensure that all team members are fully supported and foster authentic engagement and shared decision-making throughout the study.

Provide ongoing training and support: ICI staff realized that our usual weekly or bi-weekly meeting schedules did not allow adequate time for training on research itself. On many occasions, extra meetings were necessary to provide training as co-researchers had limited or no experience as researchers. Professionals who want to implement inclusive research should schedule regular check-ins throughout the research process to ensure co-researchers clearly understand the purpose of each step, troubleshoot emerging challenges, and maintain adherence to accessibility procedures. These meetings can also support co-researchers in considering findings in relation to their own positionality as people with lived experience of IDD, while interpreting results thoughtfully and objectively. Check-ins can also be used to preview upcoming phases of the research, reinforce key concepts, and strengthen shared understanding across the team. As part of training, develop accessible training materials, such as simple PowerPoints, that explain research concepts and terms (e.g., instruments, consent, data analysis).

Address institutional barriers: ICI staff had to address institutional requirements that posed challenges for co-researchers, such as mandatory Collaborative Institutional Training Initiative (CITI) training, and develop accessible strategies to meet them. Researchers can implement strategies, such as offering supported training sessions, breaking materials into plain-language modules, or coordinating with the Institutional Review Board (IRB) for alternative arrangements. Additionally, adequately compensating people for their time and expertise is critical. It is important to consider the home institution's processes for paying consultants or advisors who are not full-time employees. In some places, this may be a time-consuming, burdensome, or complex process that co-researchers need additional support and time to navigate.

Plan for flexibility: ICI staff encountered unexpected challenges, such as scheduling conflicts, technical issues during Zoom interviews, and staff turnover at the self-advocacy organizations, which caused delays and required flexibility and timeline adjustment. Researchers can test technology in advance and develop backup plans for virtual interviews to minimize disruptions. It is important to build contingency time into project schedules to accommodate training needs, scheduling challenges, or staffing changes, ensuring the project can stay on track despite unforeseen obstacles.

Conclusion

Co-researchers made substantive contributions across multiple phases of the research process, bringing their expertise, perspectives, and lived experience, strengthening the rigor and relevance of the work. The partnership with MASS and SANYS strengthened the GATOR project's findings and ensured the final products were more relevant and impactful for special educators, parents, and others seeking to improve transition outcomes for youth with IDD. Furthermore, ICI staff gained knowledge in the development and implementation of inclusive research strategies that will be useful in future research both with and about people with IDD.

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We would like to thank the co-researchers and supporters from the Self-Advocacy Association of New York State (SANYS) and Massachusetts Advocates Standing Strong (MASS).

SANYS is an organization founded and led by people with developmental disabilities for people with developmental disabilities. They promote the awareness and recognition of the civil rights and responsibilities, which include the opportunities and choices of equal citizenship.

MASS is a self-advocacy organization in Massachusetts that has been empowering and creating a platform for self-advocates since 1998. Their mission is to empower self-advocates through education so advocates make choices that improve and enrich their lives.

Self-Advocacy Association of New York State (SANYS)

Massachusetts Advocates Standing Strong (MASS) Researchers and Supporters:

Guardianship Alternatives and Transfer-of-Rights

INSTITUTE FOR COMMUNITY INCLUSION, UMASS BOSTON

This resource is a product of Guardianship Alternatives and Transfer-of-Rights (GATOR) at the Institute for Community Inclusion, University of Massachusetts Boston, and is supported in part by the Institute of Education Sciences, U.S. Department of Education, grant # R324A190114.

Suggested Citation: Domin, D., Kamau, E., Timmons, J., & Hall, A. (2026). Partnering with people with intellectual and/or developmental disabilities to design and implement research. Research to Practice No. 69. University of Massachusetts Boston, Institute for Community Inclusion.

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