Adapting Participatory Action Research to Include Individuals with Intellectual and Developmental Disabilities during the COVID-19 Global Pandemic

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Plain Language Summary

Participatory action research, or PAR, includes people with disabilities on the research team. All team members are researchers. Researchers have changed the way they do work to keep people safe from COVID-19. This is important for people with disabilities because COVID-19 is dangerous. There are still many ways for research team members to work together and learn to trust each other. This article shares some ideas for including researchers with disabilities. We can find more ways for researchers to be a part of the team. We can ask people how they like to share their ideas. We can practice sharing ideas in different ways. And we can use small groups to get things done. "Nothing about us without us" is also a goal of research. There are many ways to include people with disabilities in research. We are learning new ways to stay safe and get work done during the COVID-19 pandemic.

Despite acknowledging that individuals with I/DD are the experts on their own experiences, researchers have traditionally viewed the roles of individuals with I/DD, including autistic people,[1] as research participants rather than co-researchers or collaborators in scientific inquiry (Chown et al., 2017; Coons & Watson, 2013). In response to the recognition that the inclusion of those living the experiences being studied contributes to more relevant and meaningful research, interest in participatory research with individuals with I/DD has blossomed in recent years (Jivraj et al., 2014; Nicolaidis et al., 2019). There is still a need for continued progress in meaningful inclusion of people with I/DD in research, and the impact of the COVID-19 pandemic on research processes and its disproportionate effects on people with disabilities

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[1] There are individual preferences regarding identity-first and person-first language; therefore, we used both. We used identity-first language, which is preferred by many autistic self-advocates (Bottema-Beutel et al., 2020). We also used person-first language to refer to individuals with intellectual disability.

(Constantino et al., 2020) threatens this progress. Therefore, this paper's aim is to provide recommendations for adapting participatory approaches to research with individuals with I/DD to the COVID-19 context.

Participatory Action Research with People with I/DD

Benefits and Challenges

Participatory action research (PAR) is a pluralistic research orientation that resists traditional roles and methodologies (Chambers, 2008). PAR positions research populations in dual roles of co-researcher with shared responsibilities and opportunities for the production and consumption of knowledge throughout the research process (Borda, 1996). Participatory research has many names (e.g., inclusive research, PAR, community-based participatory research [CBPR], emancipatory research); therefore, its "umbrella definition" leaves space for individual interpretation and variations in the ways in which individuals with I/DD are included (Bigby et al., 2014; Frankena et al., 2019). Engagement in PAR shifts the balance of knowledge and power, an imbalance, which has historically oppressed and exploited vulnerable populations, including people with I/DD.

Principles of PAR maintain that all stakeholders have valuable experience, and that research must be conducted with people instead of on or even for people (Chambers, 2008), a suitable complement for the well-known mantra of the disability community, "Nothing about us without us." Inclusion of co-researchers also benefits the research team (Bigby et al., 2014; Tanabe et al., 2018). Co-researchers with disabilities can integrate their lived experiences, have developed richer methods of data collection, and add unique interpretation to the data (Bigby et al., 2014). When people with I/DD are co-researchers, they are no longer inert objects of observation; rather, the power and control of knowledge is shared.

Despite the multiple benefits of inclusive PAR, there are barriers to its facilitation that predate COVID-19. The pluralistic nature of PAR means that while participants are expected to be engaged in active participation throughout the knowledge acquisition process, the manner in which participants are involved can vary widely. Meaningful involvement of co-researchers with I/DD can be challenged by the range of accommodations necessary to ensure equitable engagement. In true PAR (Seekins & White, 2013), co-researchers with disabilities are included in research question formation, study implementation, data analysis, and dissemination of results.

Although PAR actively aims to decrease biases and move towards social justice, the micropolitics of research institutions still present in PAR spaces (Smith et al., 2010). Decision-making about research processes and management of resources are often shared between researchers who do and do not align with the core principles of PAR. Systems that have more financial resources to provide accommodations may still be burdened by outdated procedures that limit involvement of co-researchers without certain credentials. It is important to counteract biases about what constitutes sound or rigorous research and even who qualifies as a researcher.

Considerations for PAR with People with I/DD

Despite the growing emphasis on using participatory methods, there has been a lack of guidance on the "how to" or practice-based guidelines for including individuals with I/DD in research (Nicolaidis et al., 2019; Vega-Cordova et al., 2020). PAR promotes equitable, cooperative research partnerships. In theory, PAR should hold the potential to fully include people with I/DD in all phases of research, ensuring social relevance, inclusion, and accessibility (Hughes et al., 2020; Nicolaidis et al., 2015; Stack & McDonald, 2014). That potential may not be realized due to a lack of accommodations made to processes, items, procedures, or systems even with the application of universal design in the process (Centers for Disease Control and Prevention [CDC], 2020; Rios et al., 2016). More recently, researchers (e.g., Nicolaidis et al., 2019; Schwartz et al., 2020) have focused on identifying lessons learned to ensure that participatory methodologies for individuals with I/DD reflect truly inclusive, rather than tokenistic, collaborations.

A commitment to an accessible research environment is essential for the authentic inclusion of individuals with I/DD (Schwartz et al., 2020). Accommodations, such as opportunities to review materials in advance and use of plain language, facilitate the participation of individuals with I/DD in research partnerships (Nicolaidis et al., 2019; Stack & McDonald, 2018). Accommodations should be individualized; for example, people with ID may prefer brief summaries and phone or in-person contact whereas autistic co-researchers may prefer detailed explanations and communication by text or the Internet (Powers, 2017).

Prioritizing accommodations and the continued re-assessment of accommodations to ensure that individuals' needs are met communicates that researchers are sincerely committed to creating a supportive research environment for all their partners (Stack & McDonald, 2018). Relatedly, building and maintaining trust and relationships between researchers and individuals with I/DD is crucial to effective collaboration (Nicolaidis et al., 2019; Schwartz et al., 2020). Dedicated time to getting to know one another can facilitate teamwork, and icebreakers or other activities to identify shared goals can build motivation. In addition, the responsiveness and openness of researchers to feedback and evaluating the research process not only fosters trust but also improves the effectiveness of the research collaboration (Schwartz et al., 2020).

Ideally, project goals are developed collaboratively, so that all stakeholders are engaged from the start. Clear roles, goals, and responsibilities should be defined and can help to build trust and avoid future frustration or unmet expectations. Transparency about compensation and funding as well as potential funding constraints is critical, so that individuals can make informed decisions about their participation (Nicolaidis et al., 2019). Further, regardless of the type of partnership, from an advisory or consultative model to full inclusion, the thoughtful identification of co-researchers and identifying partners with particular types of lived experience for the research team is fruitful (Schwartz et al., 2020).

Several participatory projects focused on topics important to the I/DD community have used these strategies, which have contributed to more relevant and meaningful research. One group (Hughes et al., 2020) held quarterly videoconferences with a national advisory board of people with intellectual disability. Advisors chose mentors who assisted them in connecting to

the conference, reviewed meeting materials in advance, and supported their communication needs and understanding during meetings. Another participatory team adapted standardized measures by including hotlinks to define difficult terms and to provide examples, adding graphics for response options with Likert-type scales, and changing wording for purposes of clarity (Nicolaidis et al., 2015). Including individuals with I/DD as research partners enabled the researchers to increase the validity of their data collection, as standardized measures are often not accessible to people with I/DD without modification (Meyers & Andresen, 2000).

To conduct fully inclusive research, dissemination activities should include community partners with I/DD as co-authors of peer-reviewed articles and lay language briefs. They should also be involved as co-authors and/or co-presenters of presentations on local, national, or international levels (Nicolaidis et al., 2019; Powers, 2017).

Effects of COVID-19 on People with I/DD

COVID-19 has disrupted nearly every segment of peoples' lives, and it has the potential to disrupt PAR with individuals with I/DD. COVID-19 disproportionately affects people with I/DD, who are at increased risk for poor medical outcomes from COVID-19 and associated restrictions. In the U.S., individuals with I/DD experience more severe outcomes from COVID-19 (e.g., higher case-fatality rates; Landes et al., 2020). Beyond the health consequences of COVID-19, the pandemic highlights broad inequities experienced by individuals with I/DD, including the loss of in-person services on which many individuals with I/DD rely for daily living (Arc of the U.S., 2020; Constantino et al., 2020).

Moreover, the pandemic has also brought attention to the inequities embedded in society that have systematically oppressed racial/ethnic minorities for generations (e.g., lack of access to quality healthcare, discrimination). Racial/ethnic minorities with I/DD have experienced significant disruptions to their daily lives because of the lost educational, healthcare, and personal assistance services given social distancing or quarantine orders (Jeste et al., 2020; Sabatello et al., 2020). Although the historical marginalization of people of color with I/DD is documented, this population continues to be minimally represented in research (Luckasson & Schalock, 2020). The perspectives of people of color with I/DD should help guide practice, policy and research decisions that impact their health and quality of life (Luckasson & Schalock, 2020; Mello et al. 2020). The potential stagnation of research efforts because of COVID-19 threaten to further these inequities in research participation of people of color with I/DD.

Now, more than ever, a thoughtful and intentional focus on PAR is needed. Unfortunately, COVID-19 has disrupted traditional systems of conducting PAR with people with I/DD. As such, we offer potential considerations and recommendations for conducting PAR within the context of the pandemic.

Opportunities and Recommendations to Adapt Research due to COVID-19 Response

A New Context for Relationship-Building

Trust, described as "the fragile foundation of contemporary research," is an underlying component of every study (Kass et al., 1996, p. 25) and is particularly relevant and complex in the inclusion of co-researchers with I/DD. Trust is a heightened need for those who commit to collaborations during a pandemic, which can be difficult given COVID-19 social distancing guidelines. Moreover, specific attention to engaging ethnic/racial minorities with I/DD who may be disproportionately affected by COVID-19 is needed. Having culturally diverse staff members who can explain the purpose of research in a community-friendly way and in co-researchers' native languages can facilitate partnership building with underrepresented communities. Building rapport with and between co-researchers at distance and using potentially new methods of communication, like live video conferencing and email exchanges, is an emerging challenge.

Although responses to COVID-19 intensified some barriers to PAR's inclusion of co-researchers with I/DD, it decreased the impact of others. Access to transportation is a one of the biggest barriers in many aspects of life (e.g., employment, access to healthcare, community living) for people with disabilities. Shelter-in-place orders affected the supply and demand for transportation and made it harder for everyone to get around (Lyu & Wehby, 2020). As more professionals from a wide range of backgrounds conduct research and learn new ways to establish and build relationships at distance, there are more options for virtual connection. Gaining entry to a community can often take several months given logistical challenges of scheduling and transportation. With innovative applications of technology, researchers may be able to abbreviate some of these processes, but the necessity to build trust and rapport remains.

With targeted and sustained effort, PAR can support people with I/DD to participate safely via remote methods, such as video or phone focus groups, individual interviews, group interventions, and advisory board meetings. Accommodations to ensure accessibility should be individualized to meet unique needs. Questionnaires can be mailed to participants with instructions to have the paper formats available while responding to the questions administered by phone. Researchers can build the provision of Wi-Fi and electronic devices into their budgets, as these resources are often not available for people with I/DD. However, as Constantino et al. (2020) emphasized, electronic substitutions for in-person contact may not be beneficial for some people with I/DD.

Advocacy may be necessary to acquire the funding and flexibility needed to integrate accommodations as seamlessly as possible into the research team's processes. Researchers may need to allocate funding to hire culturally diverse research staff and to dedicate time for developing accommodations and cultural adaptions (e.g., translation). Researchers are increasingly under pressure from funding agencies to expedite timelines under a limited scope of budget. The benefits and challenges of PAR must be weighed against feasibility to ensure success as perceived by all parties.

Strategies to Promote Inclusive Virtual Engagement

Inherent power differentials within research teams often naturally emerge—even under the best circumstances. Virtual modalities pose challenges to aspects of team culture, including verbal and nonverbal communication, authentic relationship-building, and equal contribution from all members. PAR teams must, therefore, intentionally integrate strategies to promote opportunities for all members to contribute and ensure equitable voice. Suggested strategies are based on both the literature and the experience of the authors conducting virtual partnerships during the pandemic.

- *Provide multiple methods for team members to contribute to the conversation.* Members of the research team may have varying preferences for and level of comfort with different communication modalities. Soliciting input and feedback through verbal sharing, use of chat boxes, email, and other written options may help cultivate a group culture that honors individual preferences (Nicolaidis et al., 2011). Given that engagement in long virtual meetings can be difficult, teams may benefit from soliciting group ideas and feedback via follow-up listservs and surveys that are analyzed between meetings (Jessell et al., 2016; Tamí-Maury et al, 2017).

- *Ask about communication preferences upfront.* Relatedly, it is easy to make assumptions that we understand others' communication preferences, either based upon our own biases or based upon experience with them from in-person engagement. However, these preferences may change in concert with adaptations to our virtual work context, and technological experience within a group can be diverse (Jessell et al., 2016). Assessment of communication preferences is important when engaging individuals with I/DD under usual circumstances, and it becomes more critical in virtual contexts. For new and existing teams, we suggest explicitly exploring communication preferences with all team members and regularly revisiting this topic throughout the research process. Instructional researchers have developed simple questionnaires (Bailie, 2017), and teams can develop their own surveys that are customized to their respective contexts. Helpful topics to explore may include style (e.g., verbal versus written communication), modality (e.g., preferred apps/platforms such as Zoom chat, Slack, Teams, text, Whatsapp, etc.), and engagement strategies (e.g., Does the person want to jump in independently? Do they prefer to be called on directly for an opportunity to contribute?).

- *Provide multiple opportunities for input.* Because researchers often have tight agendas and timelines, there is a tendency for meetings to move quickly. Given the complexities of sharing in a virtual format, opportunities for feedback can be limited, which may not benefit all team members. Some may require time to process questions and ideas before being ready to offer feedback. Others may require additional time in the moment to formulate a response. Teams that continually revisit agenda items, solicit feedback both in the moment and via follow up (e.g., email, surveys), and cultivate openness to ongoing input will support meaningful

engagement for all participants, which may result in more creative and responsive research strategies (Jessell et al., 2016).

- *Create space for small group discussion.* Large, virtual groups are a difficult environment to promote equitable voice. In large settings, the onus is on individuals to be willing to break into conversation without the ability to rely on the subtle and nonverbal cues that are available in person. Many people can feel shut out of large discussions, and people with I/DD may be especially prone to this type of exclusion. Small groups provide a more conducive environment for team members to contribute to their desired level. This can be accomplished through intentionally planning small group meetings, such as identifying subcommittees that branch off of larger projects. Many teams also utilize virtual breakout rooms for more intimate conversations within the context of large group meetings. Ideally, groups of about eight promote ample opportunities for equitable contributions; however, information gathered about group communication preferences may influence ideal group size. For example, teams that include many members who prefer to use chat versus spoken communication may consider smaller breakouts.

Conclusion

Although COVID-19 exerts a major impact on research endeavors, academics and community partners can preserve the integrity of PAR by adapting processes to accommodate safe and meaningful participation of people with I/DD. Research with this population must move forward. Overlooking or postponing the inclusion of people with I/DD because of COVID-19 will only further inequities experienced by this population. Individuals with I/DD can provide positive contributions to research. Engagement in meaningful research can better the lives of participants. In addition to challenges rendered, the COVID-19 pandemic has increased the frequency of virtual methods of connection, thus potentially breaking down barriers of future participation for people with I/DD. As researchers examine ways to ensure their work is socially just and relevant, PAR is a challenging but worthwhile approach to the inclusion of people with I/DD in the research process.

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