

Intellectual and Developmental Disabilities

Lessons Learned from Research Collaboration among People with and without Developmental Disabilities

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Abstract

Research related to the developmental disability (DD) community should include collaboration *with* individuals with DD. Unfortunately, individuals with DD are infrequently involved in research projects in meaningful ways, and there is little guidance about how to collaborate equitably with researchers with DD. The purpose of this manuscript is to share lessons learned from a collaborative research study among researchers with and without DD using both qualitative and quantitative methods to develop and examine the effectiveness of a civic engagement intervention for transition-aged youth with disabilities. It includes how our research team compensated researchers with DD, clarified team member roles, leveraged the expertise of researchers with DD in using both qualitative and quantitative methods, and integrated technology throughout the research process.

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Lessons Learned from Research Collaboration among People with and without Developmental Disabilities

The long-held rallying cry from individuals with developmental disabilities (DD) has been “nothing about us without us”—all activities that address the DD community should occur with the involvement of individuals with DD. Accordingly, research related to the DD community should include collaboration *with* individuals with DD (Stack & McDonald, 2014). Collaborating with individuals with DD is valuable because it brings faculty researchers and individuals with DD together, “to generate new knowledge that neither group could do alone” (Bigby et al., 2014, p. 8). Walmsley et al. (2018) found that collaborating with researchers with intellectual disabilities (ID) allowed research teams to: recruit under-represented individuals with ID, have a greater impact in lives of individuals with ID, and reflect the “insider cultural knowledge of people with intellectual disabilities” (p.755). Researchers with DD have described their positive contributions to research projects. For example, St. John et al. (2018) explored the contributions of co-researchers with ID who worked on a qualitative research project, and found that the researchers with ID knew how to ask relevant questions of the study’s participants and helped the participants feel more comfortable.

Unfortunately, individuals with DD are infrequently, meaningfully involved in research. In two systematic reviews of research involving people with disabilities, both reviews found that individuals with DD were often minimally involved in the research process (Rix et al., 2020, Stack & McDonald, 2014). Minimal involvement often included roles such as focus group participants, or otherwise with low levels of research collaboration.

To increase the meaningful inclusion of individuals with DD in research projects, some toolkits have been developed for nondisabled researchers to collaborate with individuals with

DD (e.g. Kidney & McDonald, 2014; Nicolaidis et al., 2019; Ahlers et al., 2021). Such guidelines describe how to form a research team, build trust among team members, and promote clear communication and accessibility throughout the research process. Descriptions of collaborative research projects have provided varying levels of detail about the research collaboration. Even with such guidance, among studies which have included collaboration with individuals with DD, there is a lack of detail and transparency about the methods of inclusion, especially from the beginning (i.e., conceptualization of the project) to the end of the project (i.e., results and dissemination; Rix et al., 2020).

In this conceptual paper, we describe our ongoing research project that included researchers with DD, faculty researchers without DD, and doctoral student researchers without DD from its inception to the development and piloting of an intervention and measures. Our research project utilizes qualitative and quantitative methods to collaboratively develop and examine the effectiveness of a civic engagement intervention for transition-aged youth (14-22 years old) with disabilities in the context of the next reauthorization of the Individuals with Disabilities Education Act (IDEA).

In the project, we also collaborated with individuals with intellectual disabilities (ID) and other types of DD. Throughout this manuscript, we use the term DD, given that it refers to individuals with lifelong intellectual, physical, or both disabilities (National Institute of Child Health and Human Development). We hope that this descriptive, conceptual manuscript shares an example of how other research teams can include individuals with DD in the research process.

At the same time, we need to stress that our study did not originate with the goal of research collaboration with individuals with DD and did not adhere to a study design more suited to that goal, such as participatory action research (PAR) or community-based participatory

research (CBPR). Because we did not engage in PAR (Platt et al., 2017; Schwartz, Young Adult Mental Health/Peer Mentoring Research Team et al., 2020; Ahlers et al., 2021) or CBPR (Stack & McDonald, 2018; Strang et al., 2019), and adhered to a more traditional study design, our experiences and lessons learned may be valuable to others conducting similar studies in terms of expanding the possibilities for research collaboration with individuals with DD. We begin by sharing some of the gaps in the extant literature about how to include individuals with DD. Then, we briefly describe our research project. We discuss how our research team compensated researchers with DD, clarified team member roles, leveraged the expertise of researchers with DD in using both qualitative and quantitative methods, and integrated technology throughout the research process. We hope the detailed description of our journey as a research team can offer insight for future research collaborations involving researchers with and without DD.

Brief Review of the Literature

Appropriately Compensating Researchers with DD

Many of the guidelines and toolkits to include individuals with DD recommend fair compensation for researchers with DD (e.g., McDonald & Raymaker, 2013; Nicolaidis et al., 2019). However, specific details and examples are needed on how to do this, especially regarding compensation that does not interfere with disability benefits. Many adults with DD rely on governmental benefits that are linked to income (e.g., supplemental security income or SSI). Indeed, more than 70% of adults with ID in the United States qualify for SSI (Livermore et al., 2017). Without guidance about compensation, researchers may provide compensation that reduces disability benefits or provide limited compensation to avoid this problem.

Clarifying Team Member Roles

Research collaboration with individuals with DD has taken many forms, with varying levels of inclusion of individuals with DD (Rix et al., 2020; Stack & McDonald, 2014). Collaboration may include: reviewing materials (e.g., Hughes et al., 2020; Schwartz & Durkin, 2020; McDonald & Stack, 2016), developing questionnaires and focus group protocols (Kramer et al., 2013; Nicolaidis et al., 2021), and contributing to data collection and analysis (Rix et al., 2020). Although less common, some studies have been led by individuals with DD, with academic researchers serving as consultants (e.g., Walmsley et al., 2018; Walmsley & Central England People First History Project Team, 2014). Some academic researchers have involved individuals with DD in the research process using an advisory approach, wherein a board of advisors with DD consults on the overarching directions of the research project or specific issues that emerged through the course of the project (Bigby et al., 2014). Because the advisory approach is led and controlled by the academic researchers, it may not allow for meaningful and equitable collaboration (Bigby et al., 2014). Providing examples of how to meaningfully include individuals with DD may help increase the number of research studies with researchers with DD.

Engaging in Research Collaboration in Quantitative and Qualitative Studies

Most studies involving researchers with DD have been qualitative, primarily using focus groups and interviews to describe participant experiences and perspectives (Rix et al., 2020; Stack & McDonald, 2014). There is limited mixed method and quantitative research projects including co-researchers with DD (e.g., Kramer et al., 2014; Schwartz, Young Adult Mental Health/Peer Mentoring Research Team et al., 2020). However, of the limited extant studies, there is tremendous value in including researchers with DD in such studies. Including researchers with DD in mixed method and quantitative research would help ensure that measures and interventions center the experiences and support needs of individuals with DD; accordingly, such

research would be more effective and of higher value to individuals with DD (Clark et al., 2017; Nicolaidis et al., 2015; Nicolaidis et al., 2020; Oswald et al., 2014; Schwartz, Young Adult Mental Health/Peer Mentoring Research Team et al., 2020; Strang et al., 2019). More research is needed to understand how to include researchers with DD in mixed method and/or quantitative research.

Leveraging Technology to Include Individuals with DD in Research

Studies involving researchers with DD often utilize technology. A recent rapid scoping literature review that examined the use of technology in inclusive and participatory research with individuals with DD found that researchers used technology for: team function and formation (e.g., using online surveys to inform meeting procedures), data collection (e.g., using iPads, cameras, audio recorders, and video conferencing to collect data), analysis (e.g., using online discussion platforms for team members to discuss the data), and dissemination (e.g., using videos to disseminate the findings; Hwang et al., 2021). In addition, many studies reported providing accommodations for researchers with DD to access the technology. However, little is known about the experiences and perspectives of research team members with DD regarding the use of technology on research teams.

Developing and Testing a Self-Advocacy Intervention for Youth with Disabilities

This manuscript derived from the authors' collaborative experiences during our research study, Project BLINDED FOR REVIEW, which tests a civic engagement intervention for families of individuals with DD and transition-aged youth with disabilities in advocating for systemic change during the next IDEA reauthorization. In Project BLINDED FOR REVIEW, we aim to (1) examine the effectiveness of a civic engagement intervention for parents of K-12 students with disabilities and transition-aged youth with disabilities, (2) identify the facilitators

and barriers to civic engagement by parents and youth with disabilities, and (3) explore parents' and youths' suggestions for the next IDEA reauthorization. In a previous study (Authors, 2021), we examined the efficacy of the civic engagement intervention with parents; in the current study, we developed the youth civic engagement intervention and adapted the measures from the prior study.

Our research project includes qualitative and quantitative measures. Regarding the former, we will conduct focus groups and videotaped testimonials with parents and youth about civic engagement (e.g., legislative advocacy) and their suggestions for the IDEA reauthorization, respectively. With respect to the latter, we will administer pre-, post- and follow-up surveys with the parents and youth to determine the effectiveness of the civic engagement intervention on special education and legislative knowledge, empowerment, and civic engagement.

We had a large and diverse research team across two universities for this project. The core of the research team included two professors who are both family members of individuals with DD. The team also included six doctoral students, two of whom are family members of individuals with DD. The team included one researcher with DD per each university: one researcher with DD had cerebral palsy and one researcher had autism. Of the ten members of the research team, half were people of color and half were white. Our research team closely collaborated with six Parent Training and Information Centers (PTIs) in six respective states. Specifically, PTI staff included 13 family members of individuals with DD and three individuals with DD. For this manuscript, we relied on our agendas, meeting notes, observations, and field notes collected during the research project. Researchers with and without DD collaboratively and iteratively developed an outline, wrote, and edited the manuscript. Accordingly, we included quotes from members of the research team to help exemplify certain themes and lessons learned.

Compensating Researchers with DD

Upon writing the research grant, the Principal Investigators (PIs) contacted two individuals with DD to garner their interest in the project. The two individuals with DD were chosen because the PIs had established working relationships with these individuals. During their discussions, the PIs and individuals with DD discussed their roles in the project, method of payment, and number of part-time hours needed to participate in the project. The two individuals with DD agreed to participate and, accordingly, shared their resumes for inclusion in the grant proposal. The PIs included the agreed salary and hours in the budget.

During their initial discussions, both individuals with DD reported receiving governmental assistance. Accordingly, both individuals reported concerns about not exceeding income requirements which could jeopardize their benefits. To address this, the faculty researchers without DD and researchers with DD worked together to determine the number of hours the researchers with DD would work every month. In this way, they ensured that the researcher with DD would not exceed their income requirement.

Notably, capping the number of hours per month is not a perfect solution. Often, in research, the amount of effort undulates over time with some spans of time requiring more effort and others requiring little effort. Indeed, varying effort occurred in this project. However, having different amounts of time was problematic for the researchers with DD as too many hours could hurt their access to benefits. There was confusion about this on the part of the PI and one researcher with DD such that too many hours were being ascribed at the beginning of the project. Accordingly, the number of hours had to be dropped to stay within budget. Thus, although we made attempts at the beginning of the project to clarify the amount and type of payment, future efforts to include individuals with disabilities in research and provide appropriate compensation

should be more intentional about the number of hours, salary amount, payment method, and consistency of hours.

Clarifying the Roles of Research Team Members While Also Being Flexible

At the beginning of the project, one of the university sites defined roles for the researchers with and without DD. In particular, a researcher without DD was assigned to be a contact person for the researcher with DD from that site. The contact person provided a range of duties including helping the researcher with DD set up direct deposit and complete their timesheets, eliciting feedback about research measures, piloting measures, and facilitating their involvement during team meetings. At the other university site, a contact person was not initially designated, though the PI helped the researcher with DD complete and submit paperwork and timesheets. After noticing limited participation during the weekly research meeting, the doctoral student at this site fulfilled the role of the contact person with the researcher with DD. Identifying contact people helped ensure that the researchers with DD always had at least one individual who could provide individualized assistance, as needed.

At the outset of the project, we also tried to establish an open line of communication across all team members. We did this primarily through weekly research team meetings via Zoom. During these meetings, we encouraged everyone to participate. A researcher with DD described her participation and support at these meetings:

The PI encourages me to ask her questions, if I have any. She is also good at answering my questions, providing me with support, and accommodating my needs in whatever way she can. She is really helpful with making sure I have as much information as possible about the project, so I will know what to expect. She is really patient with me by letting

me know about this project, giving me time to think about being part of it, and accepting my decision to be part of it or not.

While the weekly team meetings were helpful in allowing for consistent communication, we made some improvements to ensure more equitable participation. For example, each team meeting utilized an agenda, but one researcher with DD reported the agendas were too general resulting in them being unsure what to prepare or what to do prior to the meeting. To ensure more robust conversation during the team meetings, agendas were revised to include more specificity and action items assigned to researchers. In addition, we had a large research team (i.e., 10 researchers altogether). A researcher with DD reported that, due to the size of the team, it was challenging to participate in the meetings and that alternatives to large meetings work better: “Since I have always had difficulties with communication, I have long found email to be an easier way to keep up with my friends and colleagues. Email continues to be a preferred communication tool for me, especially for this collaboration.” Accordingly, the researcher with DD emailed or met with their contact person researcher weekly to provide feedback.

The contact person explained, however, that while emails and individual meetings allowed the researcher with DD to contribute to the project, this system meant the rest of the research team was not always aware of the contributions of the researcher with DD:

The conversation moves quickly, however, and we do not always make space for [researcher with DD] to give feedback on the intervention. I think meeting with [researcher with DD] weekly one-on-one helps make sure that their valuable suggestions are incorporated into the intervention. By meeting one-on-one, however, the rest of the team is not always aware of the full value of what [the researcher with DD] is bringing to the team. When we meet as a group, I try to point out ways that [the researcher with DD]

has improved the intervention so that the other members of the team are more aware of their contributions.

Subsequently, we also created subcommittees among the research team dedicated to certain portions of the research project (e.g., developing the youth intervention) so researchers with DD could also participate more regularly in a smaller setting.

As described earlier, our project involves collaboration with PTIs in six states. Upon learning that several PTIs did have staff members with DD who would participate in the project, we revised the roles of the PTIs to include providing input into the development of the civic engagement intervention for the transition-aged youth with disabilities. For example, a staff person with DD from a PTI helped prepare the youth intervention and provided input about needed accommodations for the intervention. He suggested: “Ten-minute break time is not enough. For someone like me may take a little longer for stretching or bathroom breaks. The very minimum is 20 minutes. We are aiming at people with disabilities and need to make sure bathroom is accessible too.” By revising the role of the PTI to include PTI staff members with DD providing feedback about the research project, our intervention was developed with more meaningful input.

Incorporating the Input of Individuals with DD in Developing Measures and the Youth Intervention

Development of the Focus Group Protocol for Transition-Aged Youth with Disabilities

The purpose of the focus group protocol is to understand the youths’ experiences and perspectives of special education and advocacy. We collaboratively developed the protocol by adapting the parent focus group protocol for transition-aged youth with disabilities. All research team members provided feedback on the focus group protocol by editing and commenting on the

protocol and sharing feedback during meetings. Adaptations to the protocol included using plain language, making questions more concrete and specific, and adding follow-up and probing questions. For example, the research team agreed that certain terms should be defined for the youth. To this end, the focus group protocol included a plain language definition of *advocacy*: “Advocacy is when people speak up for something they need or something they believe in.” Questions from the parent focus group protocol which were broad and abstract, such as “What do you think of the structures in special education?” were broken down into more concrete and specific questions (e.g., “How many of you have been to at least one of your IEP meetings?”; “Are there things that you like about your IEP meetings?”; and “What changes would you make to make your IEP meetings better?”).

After adapting the focus group protocol as a research team, we piloted the protocol via Zoom with four youth or young adults with DD who were identified through the social networks of the research team. After the pilot focus group, we revised the focus group protocol based on the pilot participants’ responses. For example, the protocol question “What do you talk about at your IEP meetings?” was intended to identify how youth contributed to their IEP meetings. However, the pilot participants described the content of their IEP meetings generally, focusing on the contributions of school personnel and their parents. Thus, we revised the question to, “When you go to your IEP meetings, what do YOU talk about?” In addition, pilot focus group participants appeared confused by the question “Do you and your parents ever advocate for different things?” Accordingly, we rephrased the question to support participant comprehension: “Tell me about a time you disagreed with your parents when they advocated for you. Maybe there was a time when they were advocating for something but you wanted something else.”

Cognitive Interviews of the Survey Measures

We conducted five cognitive interviews to ensure the survey measures were accessible and appropriate for transition-aged youth with DD. Survey items that are not well-designed for the targeted population could lead to misleading information (Ryan et al., 2012). The survey consisted of four broad sections: Empowerment (Power et al., 2001), Special Education Knowledge (Burke et al., 2016), Civic Engagement (Lopez et al., 2006), and Self-Determination (Wollman et al., 1994). Notably, only the Transition Empowerment Scale and Self-Determination Scale have been validated with transition-aged youth with DD. Thus, we focused on our cognitive interviews on the remaining measures.

During the cognitive interviews, we identified issues with the survey measures. Specifically, during the interview, for each item, we asked if the item “made sense” and, if it did not, which part of the sentence was confusing. We learned that some terms commonly used in civic engagement created confusion among the individuals with DD. For instance, in one item, we asked, “*Have you e-mailed a legislator?*” The youth questioned the meaning of the word *legislator*. When we explained the definition of a legislator, youth suggested using the term *lawmaker* instead. Accordingly, we revised the item to read “*Have you e-mailed a lawmaker?*” We also changed “dispute resolution options” to “choices to resolve conflicts”, “assessment” to “test”, “precedes” to “happens before” and “civic engagement” to “advocacy with lawmakers” based on feedback from the cognitive interviews. The youth also suggested defining certain terms in the questions, and we revised the items accordingly. For instance, one item originally asked, “*Have you worked as a canvasser – going door to door for a political or social group or candidate?*” A youth suggested defining “canvasser” in the question.

Garnering Input about the Intervention

To elicit meaningful feedback from interested individuals with and without DD, a subset of the research team met weekly to develop the youth civic engagement intervention. The smaller group included two researchers with DD and three doctoral students. A researcher with DD liked that a smaller team met to discuss the intervention: “It might help to meet in a smaller group with a few people, or one person, to figure out what to say, what needs to be done, and what ideas we can come up with and can do together.” Similarly, a researcher without DD described the benefits and procedures of the smaller group in this development work:

I feel that the smaller youth intervention meetings provide the time and space for each member of the group to give their feedback about the intervention. At the meetings, we screen-share the outline and materials for the youth intervention and give everyone an opportunity to make suggestions. When someone makes a suggestion, we open it up to the rest of the group to respond. I often moderate the discussion, and I intend to be collaborative and share power, but I worry that I sometimes dominate the conversation and I feel that I am still working on stepping back. Still, I feel that everyone at these meetings is comfortable giving their honest opinion.

During these meetings, the researchers with DD made valuable suggestions that were immediately incorporated into the intervention. Such changes included having larger font, embedding graphics that include people with disabilities, and simplifying group activities. A researcher with DD reported, “I have really felt that I have been able to complement the material that we present by relating my own experience ‘from the other side of the desk’.” Both researchers with DD contributed their own personal examples with disability so the intervention would include real-life exemplars from the DD community. For example, a researcher with DD shared her transition goals, which were incorporated into the intervention.

After several meetings, an outline of the youth intervention was developed. We shared the outline in three meetings with each of the six PTIs (altogether $N = 18$ meetings). Each meeting was recorded and coded to identify the suggested changes to the youth intervention. For example, a self-advocate at a PTI suggested adding video clips to illustrate civic engagement in the DD community: “The Crip Camp example could also teach that distinction and related strategies. For example, I have a voice. We have team members to speak up for you to amplify your voice. Remember your voices come from you, with your opinion, you need people around you to amplify it.” A self-advocate at another PTI suggested that the intervention include connections to local disability groups: “[We] get the local, state, national advocacy groups to involve in this training and get the youth connected to local groups. Giving the youths tools and those connections and even if, as a group, they might not see change being made, but they have people surrounding them.” Based on this feedback, we made changes to the intervention including adding video clips and references to the larger disability community.

Using Technology to Leverage Input from Researchers with and without DD

This project was conducted during the COVID-19 pandemic; with social distancing restrictions in place, technology was used to facilitate communication across the research team and PTIs. All team meetings were conducted via Zoom. For simplicity, the same Zoom link was used for the weekly team meeting and the meetings with the PTIs. A researcher with DD reported, “The written information, including Zoom links sent to me for virtual meetings consistently, has helped me to learn, understand, and remember the information better.” Another researcher with DD, who has struggled at times during the project with inconsistent support from personal care attendants, emphasized accessibility: “Never in my wildest dreams did I imagine being able to attend meetings like this from my home in the past. Yet this has been my reality

because Zoom has become the standard in academia.” Thus, while a necessity, using technology like Zoom helped ensure meaningful collaboration across the research team.

Other technology was less successful. For example, the research team developed a Box folder for all of the materials and documents related to the project. Quickly, though, the Box folder became full with many materials that were difficult to navigate. The number of documents and the initial lack of organization in Box may have disproportionately, negatively impacted the involvement of the researchers with DD. A researcher with DD reported:

I am still not used to navigating through it [Box] or how all of the features in Box work in general. It takes me a while to adjust to changes and get used to learning and doing something new. Once I am comfortable enough to navigate through Box and understand how the features work, it will help me be more confident in using Box on my own.

Another researcher with DD had been unfamiliar with Box, explaining: “In the past, I have used Dropbox to store my files. When I began to work on this project, my schedule did not permit me to learn a new application. When I dedicated some time to learn Box, I discovered that it was not that difficult.” Although it may take time for team members to become comfortable using Box, we could have facilitated its use with a more systematic organizational structure and explicit instructions.

Lessons Learned

Researchers and the disability community alike agree that research should reflect meaningful and equitable collaboration with individuals with DD (McDonald & Raymaker, 2013; St. John et al., 2018). Unfortunately, few studies include researchers with DD beyond participant or advisory roles (Bigby et al., 2014). Moreover, as the extant literature shows, only a handful of studies have used quantitative or mixed methods when collaborating with individuals

with DD. In this conceptual paper, we share some successes and mistakes regarding efforts to facilitate meaningful and equitable collaboration among researchers with and without DD.

Below, we share our four main lessons learned.

Ensuring Meaningful Compensation

Our efforts at compensation shed some light on how to ensure meaningful employment for researchers with DD. None of the extant toolkits or guidance provides specific examples of paying researchers with DD (McDonald & Raymaker, 2013; Nicolaidis et al., 2019). Further, extant literature reinforces the concern of many individuals with DD and their families about losing benefits while securing employment (Nind, 2017). In this study, we tried to overcome these barriers by having initial, open, and honest communication with our co-researchers with DD about compensation.

However, our efforts fell short. Indeed, there are many ways that individuals with DD can work and still retain benefits. For example, SSI has many work incentives, but, unfortunately, less than 10% of all SSI beneficiaries utilize these work incentives (Anand & Ben-Shalom, 2018). Had our research team been more knowledgeable about these methods, we could have found ways to address this barrier without inserting a standardized number of hours per month for the researchers with DD.

Ensuring Meaningful Collaboration by Differentiating Team Roles

Differentiating team roles was critical to ensure meaningful collaboration and communication among researchers with and without DD. The faculty researchers each discussed the project, specific roles, and support needs with researchers with DD and provided support regarding logistics of compensation. Similarly, researchers with DD in prior studies benefitted from guidance and support from faculty researchers (St. John et al., 2018). Establishing a

specific contact person at each university site for researchers with DD not only facilitated meaningful participation as in prior studies (Bigby et al., 2014; Schwartz, Kramer, et al., 2020), but also allowed for advocacy around accessibility and equity of our research procedures.

Notably, differentiating team roles was insufficient to ensure equitable collaboration. Researchers with DD conveyed that the agendas and weekly research meetings were often unclear and moved too quickly, respectively. We needed to differentiate our meetings in terms of size and participation supports (e.g., clearer agendas, check-ins to see if someone has a comment, wait-time to allow for processing and possible comment) as in prior studies (Nicolaidis et al., 2019). In the same way engagement by people with DD as research participants is improved in smaller groups (Trevisan, 2020), engagement as researchers was more effective in the smaller subcommittee focused on developing the youth civic engagement intervention.

Collaborating With Other Individuals with DD Outside the Research Team

It was critical to include not just researchers with DD on our research team, but also to involve other individuals with DD in the development and piloting of the intervention and measures. Extant literature emphasizes that it is critical to conceptualize, design, and test relevant interventions for youth with DD in collaboration with youth with DD to maximize their accessibility and responsiveness (Schwartz, Kramer, et al., 2020; Wight et al., 2016). While researchers with and without DD helped inform and develop the focus group protocol, survey measures, and the youth civic engagement intervention, the feedback from others with DD, specifically the pilot focus group participants, cognitive interview participants, and self-advocates at PTIs, provided unique input that was critical for this project.

Utilizing Technology with Caution

Technology can be a double-edged sword, facilitating participation and increasing accessibility, while also creating unforeseen challenges to research collaboration. Our research team seemed to avoid obstacles due to our collective comfort with familiar technology such as email and Zoom. Quite differently than our successful use of Zoom, the use of the Box folder resulted in unexpected challenges during the beginning of the project due to the volume of material, lack of clear organization, and time to learn how to navigate it. When using technology, it is important not to assume all researchers are familiar with the program, to choose technology researchers with DD have experience with, and to allow time for researchers with DD to gain comfort and skill with the program or technology (Miller & van Heumen, 2021).

Conclusion

The description of the lessons learned on our journey as a research team can offer insight for future research collaborations involving researchers with and without DD. Because it can be easy, especially for faculty researchers without DD, to fall into their own work habits that may not be accessible to researchers with DD (e.g., using jargon), purposeful and proactive collaboration should be at the forefront of planning and implementing all research activities. Establishing specific roles, clarity about research tasks, and figuring out the most accessible ways to ensure open and regular communication among the research team were critical for research collaboration. We also recommend ensuring opportunities for researchers with DD to advocate for themselves, provide feedback on all aspects of the project, and suggest accommodations or improvements. In our study, having a contact person facilitated such advocacy and feedback. Finally, the research team must be willing to be flexible, listen to researchers with DD, and make those changes.

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