Inclusion

Planning Inclusive Research: A Comparison of Two Inclusive Dissertation Research Projects
--Manuscript Draft--

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We have attached this blank document as the "Rebuttal Letter" because the manuscript was accepted with minor revisions, and thus a rebuttal letter should not be needed.

Planning Inclusive Research: A Comparison of Two Inclusive Dissertation Research

Projects

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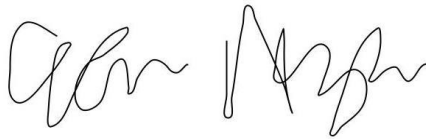
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Dear *Inclusion* Editorial Team,

Thank you for the opportunity to submit this manuscript, *Planning Inclusive Research: A Comparison of Two Inclusive Dissertation Research Projects*. We have been in communication with Dr. Karrie Shogren and Dr. Evan Dean about submitting this manuscript in consideration for an upcoming special issue on inclusive research. We think readers will be interested in this manuscript because it provides an overview of important planning components in the growing field of inclusive research. Our comparison of approaches to planning inclusive research provides examples and implications that could be valuable to new and experienced inclusive research scholars and has the potential to support the planning of future inclusive research projects. We look forward to feedback from the reviewers and editorial team.

Sincerely,

Oscar E. Hughes

Planning Inclusive Research: A Comparison of Two Inclusive Dissertation Research

Projects

Abstract: Planning inclusive research should center meaningful engagement of co-researchers

with intellectual and/or developmental disabilities to address issues that are important to their

communities. There are a variety of approaches to planning research projects consistent with the

guiding principles of inclusive research. We describe components of planning inclusive research

by comparing two inclusive dissertation research projects. We organize our comparison into five

sections: (1) initiating the projects, (2) team member characteristics and roles, (3) building and

sustaining relationships, (4) accessibility in the research process, and (5) outcomes. We then

discuss how contextual and team-level factors influence the process of planning inclusive

research.

Keywords: planning, inclusive research, participatory research, dissertation research, intellectual

disability, developmental disability

Introduction

There has been increased attention on the benefits of inclusive research to address rights, health, and participation disparities experienced by individuals with intellectual and/or developmental disabilities[1] (Jones et al., 2020; O'Brien et al., 2022; Walmsley et al., 2018). Inclusive research is an approach in which individuals with intellectual and/or developmental disabilities partner with academically-trained researchers[2] to conduct research. The term *inclusive research* was first coined by Walmsley and Johnson in 2003 (Walmsley & Johnson, 2003), and has been used as an umbrella term to describe the various approaches to active involvement of people with intellectual and/or developmental disabilities as co-researchers in the research process. Twenty years since they coined the term, Walmsley and Johnson, and colleagues, continue to emphasize five fundamental principles of inclusive research: (1) disabled people have ownership of the research problem, (2) the research furthers the interests of disabled people, (3) co-researchers with intellectual and/or developmental disabilities are involved in conducting the research, (4) co-researchers exert some control over the process and outcomes, (5) and all aspects of the research are accessible (Garratt et al., 2022; Walmsley & Johnson, 2003).

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[1] Inclusive research scholarship has often focused specifically on research by and with people with intellectual disabilities. We use the term *intellectual and/or developmental disabilities* as this is the community that we engaged with in the research projects described throughout this article. We use the term *intellectual and/or developmental disabilities* to refer to people who identify with or who have been labeled with an intellectual disability, developmental disability, or both.

[2] Throughout this article we use the phrases *academically-trained researchers* and *academic researchers* to refer to researchers who have received formal academic training to conduct research. Academic researchers typically have advanced degrees and are affiliated with a university or research institution. We use the phrases *co-researchers with intellectual and/or developmental disabilities* or just *co-researchers* to refer to people who identify with or who have been labeled with an intellectual disability, developmental disability, or both, who serve as collaborators on research projects, and do not have formal training and advanced degrees related to conducting academic research. We chose this terminology because we feel it names a distinction between team members that is relevant at the time of publication and communicates respect for all members of the team. We expect that terminology to describe disability and inclusive research teams will continue to change and evolve over time. In some cases, individuals with intellectual and/or developmental disabilities have dual roles as academic researchers and co-researchers, but this was not the case in either study described in this article.

How to plan, conduct, and disseminate research according to these principles is of ongoing discussion in the field of inclusive research (O'Brien, 2022). There is wide variation in the extent to which inclusive research teams plan to involve co-researchers at various stages of the research process, from soliciting input from advisory board members at a few predetermined stages of the study, to intentionally following the lead of co-researchers from beginning to end. A common focus of this literature is the extent and authenticity of co-researcher involvement in inclusive research projects. For example, Bigby and colleagues (2014) proposed a framework conceptualizing three different approaches to co-researcher involvement in various phases of inclusive research: advisory, leading and controlling, and collaborative groups. There is continued debate about what constitutes inclusive research, as some scholars question projects which claim to be inclusive, but document little to no involvement of co-researchers with intellectual and/or developmental disabilities, and therefore do not reflect the core principles of inclusive research (Stack & McDonald, 2014). Recently, inclusive researchers have sought to generate consensus statements (Frankena et al., 2019) and practice guidelines (Nicolaidis et al., 2019) to guide academic researchers as they embark on inclusive research partnerships.

Central to these inclusive research principles, frameworks, and guidelines is the importance of purposeful planning for inclusive research. For example, in a consensus statement written by an international team of inclusive research experts with and without disabilities, Frankena et al. (2019) state as attributes of inclusive research, "deciding upon the research topic, research questions and methods by means of dialogue with team members" and "good collaboration starts before the onset of the study and continues through all stages of the study, as far as possible given funding and time constraints" (p. 6). Planning helps teams articulate shared understandings, determine roles, and establish processes for collaboration. There are a variety of

approaches to how inclusive research is planned and who has power and control in the planning process. For example, inclusive research projects may be planned by various stakeholders, such as academically-trained researchers, governmental or non-profit organizations, or by individuals or groups of people with intellectual and/or developmental disabilities (Bigby et al., 2014; Jones et al., 2020). Additionally, some inclusive research projects are planned from the beginning with great specificity, with or without the initial involvement of people with intellectual and/or developmental disabilities, while other projects are planned broadly and then developed by the research team as the project progresses (Kim et al., 2022; White & Morgan, 2012). Planning for inclusive research often involves an ongoing process of continuous monitoring and feedback, in which roles, team processes, and goals are adjusted throughout the project. In all planning approaches, how and by whom inclusive research projects are planned impacts teams' processes and outcomes.

The planning of inclusive research is often influenced by team-level and contextual factors. Team-level factors that may influence decisions regarding teams' processes and activities include study design and the interests and skills of team members. For example, Walmsley et al. (2018) argue that the decision whether to provide traditional research training about scientific research processes and methods to co-researchers with intellectual disabilities should be based on the design and aims of the study, as well as the skills and preferences of the co-researchers on the project. Contextual factors often greatly influence the extent to which teams plan to engage co-researchers. These factors include Institutional Review Board (IRB) requirements, funding, grant timelines, and institutional beliefs about the value and feasibility of inclusive research (Flicker et al., 2007; McDonald & Stack, 2016; O'Brien et al., 2022; Walmsley et al., 2018). For example, inclusive researchers have described how grant timelines

and lack of bridge funding between projects can be a barrier to in-depth collaborative planning for some inclusive research teams (Frankena et al., 2019). Thus, the planning process for inclusive research is greatly influenced by multiple factors that uniquely interact in each project.

The purpose of this manuscript is to discuss components of inclusive research planning and the team-level and contextual factors that influence planning by comparing two different planning approaches. Specifically, we compare two inclusive dissertation research projects: *The Rainbow Inclusion Speaking Up (RISE Up) Project*, a collaborative group project that was initiated by a community organization run by and for people with intellectual and/or developmental disabilities, and *Developing a Peer Delivered Mental Health Intervention*, a project in which an academically-trained researcher recruited a team of co-researchers with intellectual and/or developmental disabilities to conduct foundation-funded research. First, we provide an overview of these two projects. Then, we refer to inclusive research literature to describe five components of inclusive research planning: (1) initiating the projects, (2) team member characteristics and roles, (3) building and sustaining relationships, (4) accessibility in the research process, and (5) outcomes. For each of these five components, we compare how our projects were planned. We hope this comparison, grounded in inclusive research literature, generates reflection on the potential benefits and drawbacks of different approaches to planning for inclusive research. Furthermore, we hope that the presentation of two inclusive dissertation projects conducted by PhD students can help other students and academic mentors better understand and plan for early-career inclusive research.

Research Projects and Positionality

The first author, [name], was conducting *The RISE Up Project* at the time this article was written ([first author], 2023). The project is his current dissertation research as a PhD student at

[university name] within the College of Education and Human Development. [First author] is a former special education teacher of students with extensive support needs who pursued a doctoral degree with the hope of promoting self-determination for youth and adults with intellectual and/or developmental disabilities. He was unaware of inclusive research when starting the PhD program–his interest in self-advocacy led him to learn about and decide to conduct inclusive research, to strive for self-determination in the design and outcomes of his dissertation project. Through his involvement and employment with the self-advocacy organization [organization] and because of his own identities within the LGBTQ+ community, [first author] became involved with the [organization and website], which is a program that provides support groups, training, and resources by and for LGBTQ+ people with intellectual and/or developmental disabilities. [First author] is a white gay transgender man who does not have an intellectual or developmental disability.

Developing a Peer Delivered Mental Health Intervention ([second author], 2020) was planned while the second author, [name], was a PhD student also at [university name] within the College of Health and Rehabilitation Sciences. [Second author] had entered graduate school with the goal of learning inclusive research approaches with young adults with intellectual and/or developmental disabilities, and her PhD training was centered on this goal. Prior to the present research, she had experiences conducting inclusive research with her PhD mentor but had not led inclusive research at the onset of her dissertation. [Second author], herself, has no disabilities, and her interests in inclusive research stemmed from her background in Disability Studies and disability rights advocacy.

Both [first author] and [second author] attended [university name] in different departments, with [first author] beginning his graduate program the semester after [second

author] had graduated. Of note, [second author's] PhD mentor used an inclusive research approach in her own work with young adults with intellectual and/or developmental disabilities. However, [first author's] PhD mentor was new to this approach, and [first author] largely drew upon the literature, including the work of [second author], to guide his thinking about inclusive research. The authors met for the first time during the first year of [first author's] PhD program to discuss his emerging interest in inclusive research. At the time the current article was written, [second author] was serving as a member of [first author's] dissertation committee.

Comparing Planning Approaches

In the sections below, we describe how planning for inclusive research can involve initiating the project, determining team member characteristics and roles, building and sustaining relationships, preparing for accessibility in the research process, and planning inclusive research outcomes (Frankena et al., 2019; Nicolaidis et al., 2011). We draw from the inclusive research literature to justify the importance of these five components of planning inclusive research, then provide narrative examples comparing how each of our projects were planned. Finally, we discuss implications of the similarities and differences in our planning approaches and highlight planning considerations for future inclusive research projects.

Initiating the Projects

Inclusive research teams have documented a variety of approaches to initiating inclusive research projects. Many inclusive research projects are initiated at universities or governmental organizations by academically-trained researchers, who then recruit people with intellectual and/or developmental disabilities to serve as advisors to the project or as collaborators on the research team (Bigby et al., 2014; Frankena et al., 2019; Jones et al., 2020; Stack & McDonald, 2014). Projects that are initiated by academically-trained researchers and later recruit co-

researchers may be less likely to address the needs and priorities of people with intellectual and/or developmental disabilities themselves, since the research topic and questions are often determined before co-researchers are brought on board (Stack & McDonald, 2014). In these cases, power imbalances and limited co-researcher ownership may be more likely, given the role of the academic researchers in designing the project and selecting co-researchers (Stack & McDonald, 2018). However, this approach to initiating inclusive research is common because it is perceived as most compatible with requirements of research institutions (e.g., grant application timelines, funding availability, and IRB procedures; Barnes, 2003; Schwartz et al., 2020).

Inclusive research projects may also be initiated by individuals or groups of people with intellectual and/or developmental disabilities who are interested in exploring a particular topic, often for the purpose of social change (Bigby et al., 2014; Kidney & McDonald, 2014). When individuals or organizations of people with intellectual and/or developmental disabilities initiate research projects, these co-researchers often have power to set research priorities and ask research questions that are more relevant and more actionable than those of academic researchers (Frankena et al., 2019; Northway et al., 2014; Walmsley et al., 2018). The significance of co-researcher initiation has been described as especially important when co-researchers have multiple identities which have been historically marginalized and misrepresented in research (e.g., Black people with intellectual and/or developmental disabilities, trans and gender-diverse Autistic youth; Johnson et al., 2021; Strang et al., 2019).

Alternatively, there are some examples of inclusive research teams consisting of academic researchers and co-researchers with intellectual and/or developmental disabilities which form independent of research funding and then collaboratively pursue funding as a team (Stack & McDonald, 2014). For example, the Inclusive Research Network in Ireland funded by

the National Federation of Voluntary Service Providers, Trinity College, and University College

Cork collectively identifies research topics and subsequently pursues funding (K. Johnson et al.,

2014). Similarly, in Wales, Barod is a "Human Interest Company" that conducts research the

team initiates and is contracted to do (Barod, n.d.). In the United States, the Academic Autism

Spectrum Partnership in Research and Education (AASPIRE) was founded by autistic and non-

autistic researchers to conduct studies desired by Autistic communities (Nicolaidis & Raymaker,

2015). In these research teams, academic researchers and co-researchers with intellectual and/or

developmental disabilities typically work together.

Although there are a variety of approaches to initiating inclusive research projects, in all

cases, project initiation influences how research foci are identified, the formation of the research

team, and how team member roles are established. These can subsequently impact how the

research is conducted and the outcomes of the project. Our two inclusive research projects were

initiated quite differently, which impacted the planning of our projects. *The RISE Up Project* was

initiated by an organization of people with intellectual and/or developmental disabilities, while

Developing a Peer-Delivered Mental Health Intervention was initiated by [second author].

Initiating The RISE Up Project

The RISE Up Project was initiated by [co-researcher], the founder and coordinator of the

[organization], a community organization led by and for LGBTQ+ people with intellectual

and/or developmental disabilities. [First author] had been working with [co-researcher] for over a

year, co-leading training and assisting with the [organization]. During a work meeting with [first

author], [co-researcher] stated that she was wondering about other projects her organization

could work on to support LGBTQ+ people with intellectual and/or developmental disabilities. At

that time, [first author] was a second-year PhD student. He was broadly interested in research on

self-determination, had just taken a course about participatory action research, and was starting

to consider what his dissertation project might be. When [co-researcher] brought up wanting to

work on more projects to support LGBTQ+ people with intellectual and/or developmental

disabilities, [first author] suggested that they collaborate on a research study. [Co-researcher]

was interested in the idea, thus, *The RISE Up Project* was initiated by [co-researcher] and the

mission of her organization, supported by [first author's] suggestion and position as a doctoral

student. ==If [first author] was not a researcher who was also [co-researcher's] assistant and friend,==

==it seems unlikely that [co-researcher] would have looked for an academic research partner or==

==conducted a research project.== Although [first author] was not yet at the dissertation phase of his

doctoral program, he was familiar with scholarship describing how inclusive research can often

take longer than other approaches (Nind et al., 2016; Stack & McDonald, 2014; Walmsley et al.,

2018), and thus was eager to start his dissertation research early.

Because the project began with [co-researcher]'s interest in improving the lives of

LGBTQ+ people with intellectual and/or developmental disabilities, the design of the research

study was centered on developing a subsequent action research project to improve quality of life

for people with those identities. In this way, *The RISE Up Project* was planned from the

beginning to have two stages: first, the initial qualitative study of the experiences and

perspectives of LGBTQ+ adults with intellectual and/or developmental disabilities, and second,

the action research project. [First author] and [co-researcher] proceeded to plan the first stage of

the project knowing that they could not yet know the details for the action research project. They

then engaged in a second round of planning for the second stage once the action research project

was chosen.

Initiating Developing a Peer-Delivered Mental Health Intervention

Conversely, [second author's] interests drove the initiation of the *Developing a Peer-Delivered Mental Health Intervention* project. This project aimed to address a gap in mental health services for young adults with intellectual and/or developmental disabilities by developing and delivering a peer-delivered psychoeducational intervention. Through [second author's] personal and research relationships with young adults with intellectual and/or developmental disabilities, she had observed the discrepancy between mental health needs and services for this group. Further, she had recently worked with her PhD mentor on a project exploring the mental health needs of young adults, which identified inadequate social supports and a lack of trained professionals ([second author], 2019). She thought a solution to these challenges may be a peer-delivered mental health intervention. As [second author] was entering the dissertation phase of her education, she applied for external funding to develop a peer mentoring intervention to address service gaps. Because she had experience with and strong commitments to inclusive research, the grant application articulated the value of and adequately budgeted for a robust inclusive research process.

Both of our inclusive research projects were initiated because we personally valued inclusive approaches to research addressing topics relevant to people with intellectual and/or developmental disabilities. However, the two projects were initiated quite differently: *The RISE Up Project* was initiated after a conversation between [first author] and a self-advocate leader who was asking questions about future directions for her organization, whereas *Developing a Peer-Delivered Mental Health Intervention* was initiated by [second author] based on her interest in addressing a service gap. The different approaches to initiating our projects influenced how our research teams formed and the characteristics of the co-researchers on our research teams.

Team Member Characteristics and Roles

Inclusive research literature suggests that team member characteristics and role clarification are essential and interrelated components of project initiation and team formation (McDonald & Stack, 2016; O'Brien et al., 2014; Puyalto et al., 2016). Conducting research will not be inherently motivating or a good match for all individuals – with or without disabilities. In community-initiated projects, co-researchers are often members of self-advocacy organizations or other advocacy groups, have leadership skills, and are experienced in identifying issues, working in teams, and problem-solving (Bigby et al., 2014; Garcia-Iriarte et al., 2009; Schwartz et al., 2020). As research may be a new experience to many, teams that recruit collaborators with intellectual and/or developmental disabilities may choose to recruit based on personal or professional experience relevant to the specific research topic, or self-advocacy experience (Schwartz & Durkin, 2020; Strang et al., 2019). In addition to lived experiences and skills, scholars have described how shared values are an important foundation for inclusive research teams (McDonald & Stack, 2016; Nind & Vinha, 2014; Schwartz et al., 2020). Recruiting collaborators solely on the basis of an intellectual and/or developmental disability diagnosis or identity may be tokenizing, as it can assume there is a universal 'intellectual and/or developmental disability perspective,' discount the importance of lived expertise, and may neglect to recognize the unique skills and motivations needed for research (Bigby et al., 2014; Nicolaidis et al., 2019).

Clearly communicating team member roles often occurs at the beginning of research partnerships. Shared understanding of roles is essential for working together and establishing mutual trust and respect (Frankena et al., 2019; McDonald & Stack, 2016; Nicolaidis et al., 2019). Team member roles may be driven by multiple factors, including team member characteristics (i.e., interests, skills, availability), funding (i.e., how much time the team can

work together), study design, and IRB requirements (Ham et al., 2004; Nicolaidis et al., 2011). Within any inclusive research approach, team member roles may need to be adjusted as the research project progresses (Kim et al., 2022; Nind & Vinha, 2014).

Inclusive research teams have recommended fair compensation for co-researchers with intellectual and/or developmental disabilities, and transparency about how much and for which tasks they will be compensated (Kim et al., 2022; Nicolaidis et al., 2019). Team members who pursue funding for inclusive research projects should make a concerted effort to secure compensation for co-researchers with intellectual and/or developmental disabilities (O'Brien et al., 2022). In our experiences, the characteristics of co-researchers and team member roles were largely influenced by how our projects had been initiated and contextual factors.

The RISE Up Project Team

For *The RISE Up Project*, [first author] and [co-researcher] agreed that [co-researcher] would be one of the co-researchers because she had initiated the research idea and was the founder and coordinator of the [organization]. They then planned to invite two other self-advocates who identified as LGBTQ+ persons with an intellectual and/or developmental disability, so they could speak from their personal experiences of different identities within these intersecting communities. [Co-researcher] already had someone in mind who held a leadership position within the [organization] and had expressed interest in getting more involved in advocating for LGBTQ+ people. They told this potential co-researcher about the grant application and possibility of working on the project if it was funded. [First author] suggested to [co-researcher] that they also strive to include a self-advocate who was Black, Indigenous, or a person of color, so that they did not have an all-white research team, and [first author] had a few people in mind from the [organization] to reach out to.

[First author] determined the roles for the first stage of the project when he applied for an internal graduate student research grant. [First author] proposed that the funding be used to compensate the co-researchers and participants. He strove to pay co-researchers a high rate to represent the value of their contributions and chose a co-researcher stipend based on the grant amount and anticipated number of hours spent working on the project. The stipend was equal to about $20 per anticipated hour of work and was paid in two parts at the middle and end of the grant period. This payment schedule was at the request of the grant administration office.

Based on his understanding of IRB requirements, [first author] believed that any co-researchers interacting with human subjects and their identifiable information would need to complete the required human subjects research training, CITI Training. [First author] had taken the training himself and felt that it was not designed to be accessible to people with intellectual and/or developmental disabilities (e.g., the training required reading large amounts of text, which included dense academic language). The small grant to which [first author] was applying would not have allowed for enough funding to compensate the co-researchers to complete the human subjects training or to meet for a substantial number of hours. [First author] also had concerns about the amount of time that the research project would take, especially as a student striving to complete and defend his dissertation within the timeline of his fellowship funding. For these reasons, he felt that asking co-researchers to complete the human subjects training and collaboratively develop the research design would take too long and be too expensive. Thus, [first author] proposed that [co-researcher] and the two other co-researchers not directly engage in data collection and analysis during the first stage of the project, and [first author] would conduct the interviews and an initial analysis of the data. The role of the co-researchers during the first stage would be to provide suggestions and feedback on the interview protocol, engage in

a secondary analysis of the deidentified data, and then have decision-making power to choose an action project for the second stage of research.

[First author] aspired for the action research project in the second stage to be more collaborative and to shift more direct control to the co-researchers. At that time, he did not know how the action project would be funded or its potential costs. He intended to apply for additional funding if needed when they reached the second stage in the project and did eventually apply for an internal diversity and inclusion program grant. For the second grant, [first author] proposed a higher stipend of $25 per anticipated hour of work, because the co-researchers would have more involvement at this stage. [First author] spoke with [co-researcher] about these ideas, and she was supportive of the research approach and subsequent action project collaboration. Later, once the co-researchers decided to write a guidebook as the action project, team members' roles were decided collaboratively by [first author] and the three co-researchers. For example, the research team later agreed that they would like all decisions about the guidebook to be made by consensus between all four members of the team.

The Developing a Peer-Delivered Mental Health Intervention Team

The *Developing a Peer-Delivered Mental Health Intervention* team formed quite differently. In the grant proposal, [second author] planned for co-researchers to have an active role in co-designing the intervention and collecting and analyzing data related to social validity. After intervention development, co-researchers would then serve as peer mentors.

These planned roles influenced the selection of co-researchers. Prior to funding, through relationships developed during volunteering and her PhD mentor's work, the second author had secured the interest and support of community-based organizations and a school-based transition program for recruitment of co-researchers. After receiving funding, [second author] identified

potential co-researchers by working with these community partners. Interested co-researchers completed an interview during which they learned about research and the research topic. [Second author's] main priority was to identify co-researchers who were enthusiastic about the research topic, had the communication skills to eventually serve as a peer mentor, and had an interest in and personal connection to mental health. She assumed that if these characteristics were present, she would be able to provide accommodations needed for each co-researcher. During interviews, applicants shared why they were interested in the topic, and completed two example research activities (providing feedback on materials and categorizing quotes). The purpose of these activities was to introduce the prospective co-researchers to the type of work they would be doing and for [second author] to observe foundational skills related to articulating opinions (critical for developing the intervention) and categorizing information (a skill related to data analysis). Additionally, as she knew she was asking co-researchers for a significant time commitment – 2 hours per week while developing the intervention, and up to 5 hours per week during peer mentoring – she therefore hoped to expose applicants to tasks they would do to help them make an informed decision about their involvement. After the interview, individuals had opportunities to discuss information with people who supported them and ask additional questions.

When selecting student research assistants to be on the team, [second author] sought individuals who had a strong understanding of disability rights and would be able to promote cognitive accessibility of materials and activities by breaking down tasks and rephrasing information. She also looked for research assistants who had the social skills to develop strong rapport with young adults with a wide range of interests and personalities.

When discussing team roles at the beginning of the study, [second author] emphasized the importance of lived expertise. Co-researchers understood that their role was to provide feedback based on their experiences and their beliefs about what other young adults with intellectual and/or developmental disabilities may experience, feel, and/or perceive. [Second author] explained her role as helping to make sure the team designed the intervention. Yet, she was also their employer, responsible for selecting co-researchers, paying them, and, at the request of some co-researchers' school staff, providing feedback on job performance. Thus, while second author attempted to shift power to the co-researchers by actively seeking and acting on their input, trialing all co-researcher ideas, and engaging in reflective practice to foster a sense of ownership in each meeting, she remained their employer and in a clear position of higher social capital. Co-researchers were paid $20 per hour for their work and their transportation was provided. She felt that paying the co-researchers this relatively high hourly rate (higher than her student research assistants) would demonstrate her value for their time and expertise. Compensation for transportation was an important way to promote accessibility. She budgeted for a wide range of transportation, including public transportation, paratransit, family/PCA transportation and parking, and rideshare.

In both of our projects, we largely determined the roles of the co-researchers as the academically-trained researchers, but also planned for opportunities for increased decision-making power throughout the projects. *The RISE Up Project* research team started with the self-advocate who proposed the research idea, and then planned to include two other self-advocates who they already knew and whose personal identities and experiences were relevant to the research topic. Therefore, the team member's characteristics played a role in how [first author] identified their roles. In contrast, [second author's] needs and pre-planned co-researcher roles

drove her to identify specific characteristics needed in co-researchers. In *The RISE Up Project*,

[first author] planned to conduct many of the research activities himself and meet periodically

with the co-researchers for suggestions and feedback at specific stages of the project. He then

planned for the co-researchers to have decision-making power for the second stage of the project

and to shift to a more collaborative process as they conducted their action research project. While

[second author] planned for her team to collaboratively engage at each step through designing

the intervention and interpreting findings, her institutional power, position as an employer, and

overall leadership were clearly visible makers of unequal power. In both examples, our

relationships with our research team also impacted how we planned our projects.

Building and Sustaining Relationships

The inclusive research literature emphasizes the importance of relationships between

team members. Many inclusive research partnerships must grapple with inherent power

imbalances, as people with intellectual and/or developmental disabilities may not have

previously had access to the settings in which research is conducted (and as co-researchers, their

access is still limited). Trust has been consistently highlighted as underpinning successful

collaborations. Trust may be built and maintained through shared goals, following through on

feedback/input, transparent communication, and spending informal time together as a team

(Kidney & McDonald, 2014; Nicolaidis et al., 2019; Nind & Vinha, 2014; Schwartz et al., 2020;

Stack & McDonald, 2018).

In some cases, prior relationships can be an asset to team members. Co-researchers may

feel comfortable working with individuals they know from other settings and feel that their prior

relationships with academic co-researchers and other co-researchers with intellectual and/or

developmental disabilities are important for teamwork (Chalachanová et al., 2020; Loeper &

Schwartz, forthcoming; McDonald & Stack, 2016; Myers, in press). In other cases, prior

relationships between academic researchers and co-researchers with intellectual and/or

developmental disabilities have the potential to be coercive, as co-researchers may perceive

personal or professional risks to withholding participation (Marshall et al., 2012). While [first

author's] team all had existing personal and professional relationships, [second author's] team

was composed of some people who knew each other and some who did not.

Relationships on The RISE Up Project Team

Before *The RISE Up Project* started, [first author] and [co-researcher] had known each

other for over a year. They met because they had facilitated training together, and then [first

author] was hired by [co-researcher] as her supporter; following her lead and assisting with the

projects she coordinated. This relationship facilitated recruitment of the additional co-

researchers, who [first author] and [co-researcher] both knew. The additional two co-researchers

had also received support from [first author] through their involvement in the [organization].

This facilitated trust and shared power on the research team because [first author] had already

demonstrated a commitment to valuing self-advocates' perspectives, following their lead, and

supporting projects they directed. Also, everyone on the research team was aware of their shared

identities within the LGBTQ+ community, which was often a source of bonding between team

members. [First author] feels that the fact that all four of the research team members already

knew each other well and had positive relationships, helped facilitate honest and equitable

communication on the research team.

Relationships on the Developing a Peer-Delivered Mental Health Intervention Team

[Second author] felt strongly that the team needed to foster trust to work together,

especially because they were likely to share personal experiences related to mental health. While

[second author] had an existing relationship with one co-researcher, she had not met the remaining four prior to their interviews. Despite her broad recruitment efforts, all the co-researchers came from the same high school transition program. While one had graduated, the other four were currently in school together, and the team members had varying current and past relationships with each other. To facilitate trust within the team, each meeting began with an icebreaker. [Second author] also ensured there was time to discuss day-to-day occurrences at the beginning of meetings and during breaks. This time to socialize fostered bonds between the co-researchers with intellectual and/or developmental disabilities and the academic researchers. [Second author] also aimed to be transparent regarding all decisions and openly acknowledge her own mistakes and lack of knowledge to further facilitate trust between herself and the co-researchers.

Prior relationships (or the lack thereof) influenced how we planned our research projects. Given the newness of relationships within her team, [second author] intentionally devoted project resources to developing trust and shared experiences. She also made efforts to earn the trust of co-researchers. In contrast, *The RISE Up Project* commenced within the context of longstanding, trusting relationships. Therefore, while [first author], worked to maintain trust, he did not have to plan activities and structures to build trust within *The RISE Up Project* team.

Preparing for Accessibility in the Research Process

Inclusive research literature has emphasized how accessibility of the research process can foster power sharing and is a requirement for co-researchers with intellectual and/or developmental disabilities to have opportunities to make meaningful contributions to the research project (Herer & Schwartz, 2022; Kidney & McDonald, 2014; Kramer et al., 2011; Marshall et al., 2012; Nicolaidis et al., 2019; Schwartz et al., 2020). Inclusive research scholars

have published guidelines and toolkits that discuss strategies to prepare for access to the research

process (Kidney & McDonald, 2014; Kramer et al., 2022; Nicolaidis et al., 2019; O'Brien, 2022;

Preparing Individuals with IDD for Engagement in Research During Public Health Emergencies

and Disasters Research Team, 2020). Some of these recommendations include: written

information in plain language, synthesizing large quantities of data into themes, breaking down

tasks, and sending materials to be reviewed in advance (O'Brien et al., 2014).

Scholars have also discussed how inclusive research teams may need supporters who

facilitate the meaningful engagement of co-researchers, without controlling their involvement or

overstepping their role (Bigby et al., 2014; Nind & Vinha, 2014). Some co-researchers with

intellectual and/or developmental disabilities have discussed the value of training and guidance

from academically-trained researchers so they could feel prepared and become more skilled and

independent conducting research (Herer & Schwartz, 2022; Kramer et al., 2011; St. John et al.,

2018). Ultimately, the accommodations, support, and training provided to co-researchers should

be based on the individual needs and wishes of the co-researchers themselves. In both of our

projects, we took similar approaches to how we prepared for access to the research process,

incorporating general accessibility strategies from the beginning (e.g., sending materials in

advance, use of plain language, allowing time for processing information) and making

accommodations throughout our projects based on the individual needs and wishes of members

of our research teams. Below we each highlight just one example of how preparing for

accessibility impacted how we planned a specific component of our projects.

Accessibility and The RISE Up Project

At the start of the second stage of *The RISE Up Project*, [first author] and the co-

researchers collaboratively planned the research process based on the strengths, availability, and

access needs of the team. Specifically, the team collaboratively developed an iterative process

for writing the guidebook chapters. First, the co-researchers would share major points for the

chapter and [first author] would take notes. Then, [first author] would write a chapter draft and

the team would meet to read and edit the draft aloud. Each member of the team would nominate

stakeholders from whom to solicit feedback on the chapters, and finally the team would meet to

decide what feedback to incorporate into the guidebook.

Accessibility and Developing a Peer-Delivered Mental Health Intervention

Based on her previous experiences, [second author] knew that a potential barrier to co-

researchers taking on roles in data collection, intervention delivery, and data analysis was the

requirement for all co-researchers to complete university-approved research ethics training.

[Second author] and her PhD mentor has already conducted inclusive research at their university

and had established a relationship with the IRB. [Second author] engaged in discussion with her

IRB about the roles of co-researchers and it was decided that since no co-researcher would have

primary responsibility for data, consent, and/or data collection (i.e., [second author] would be

present for and overseeing all activities), it was appropriate for her to deliver a modified,

accessible research ethics training to the team. She subsequently developed a training specific to

the roles of the co-researchers on the project and provided it to the IRB for approval; it was

approved without requests for modification.

Planning for Research Outcomes

Inclusive researchers have argued that research teams should thoughtfully consider how

to disseminate their research in ways that are accessible and meaningful to both academically-

trained researchers and to people with intellectual and/or developmental disabilities and their

supporters (Garratt et al., 2022). However, time and conflicting priorities can be significant

barriers to inclusive dissemination. For example, co-writing can be time consuming and may occur after funding has ended (Riches et al., 2020; Strnadová & Walmsley, 2018) and there is often little funding available for co-researchers to present their research at academic conferences (O'Brien et al., 2022). Consequently, co-researchers may be asked to engage in laborious work without compensation; and may subsequently decline the opportunity to co-write. Regardless of who writes academic articles about the research, these articles may be inaccessible to co-researchers because they are not written in accessible language or are published behind paywalls. Additionally, while academic researchers are incentivized to publish their findings in academic journals, co-researchers may not benefit from this activity. Planning for inclusive research dissemination can help to mitigate some of these barriers so publications can be authored and presented inclusively (Frankena et al., 2019).

In addition to the immediate benefits of the research process and the dissemination of the findings to academic audiences, inclusive research teams should plan projects which contribute to sustained efforts toward long-term social changes desired by people with intellectual and/or developmental disabilities (O'Brien et al., 2022; Stack & McDonald, 2014; Walmsley et al., 2018). For example, inclusive research teams can plan for outcomes such as plain language texts, video presentations, advocacy actions, and/or art installations (K. Johnson et al., 2014; Jurkowski, 2008; Nicolaidis et al., 2019). As with any research partnership, it is ideal to plan authorship and outcomes at the beginning of the research study. These discussions may help teams identify meaningful products and prospectively plan for mutually beneficial dissemination processes and outcomes. Our projects took different approaches to planning for the outcomes of the research.

Planning The RISE Up Project Outcomes

[First author] wrote in the initial grant application that the study findings would be shared in multiple ways, including: (1) an academic research article, (2) a conference presentation, (3) a practice-centered article in a practitioner journal, and (4) an accessible summary and/or presentation for self-advocacy groups to post online. Additionally, because the research was initiated by [co-researcher] and her ongoing work with the [organization], we began to incorporate findings from the interview study into [organization] webinars and presentations as soon as we began analyzing the first interviews. Thus, the research was shared with the broader community throughout the project, long before we started writing academic manuscripts. [First author] and [co-researcher] planned for the co-researchers to develop an action project that they hoped would have a direct impact on LGBTQ+ people with intellectual and/or developmental disabilities. Because the purpose of the action project was to impact the broader community, sharing the research beyond an academic audience was inherent to the goals of the project from the beginning. In fact, the action research project eventually selected by the co-researchers was to write a free and publicly-available guidebook for families and professionals about supporting LGBTQ+ people with intellectual and/or developmental disabilities (now available at [website]). We planned to share the guidebook with members of the [organization], disability service providers, state agencies serving people with disabilities, and local family organizations. We also planned for the guidebook to include information on joining and donating to the [organization] and how to hire LGBTQ+ self-advocates to deliver training, thus also promoting the growth of their organization and creating employment opportunities for people with intellectual and/or developmental disabilities.

Planning Developing a Peer-Delivered Mental Health Intervention Outcomes

[Second author] did not plan for how the research would be shared with people with disabilities. She proposed to disseminate through academic manuscripts but did not anticipate how outcomes would be meaningful to people with intellectual and/or developmental disabilities beyond the development of an intervention that she hoped would fill a service gap and be socially valid. She did eventually work with the team to determine several accessible dissemination channels, giving each individual team member the option to participate in podcasts, conference presentations, the production of a video hosted on YouTube, and academic manuscripts. However, none of these opportunities were discussed or planned at the onset of the project; rather, they were discussed as opportunities arose. Further, nearly all dissemination channels occurred primarily within academic venues, rather than settings that directly reached people with intellectual and/or developmental disabilities (e.g., self-advocacy groups/conferences, social groups, etc.) Had [second author] developed this project with the team from the start, likely they would have mutually identified valued outcomes, including meaningful dissemination outlets.

Discussion

Thoughtful planning is especially important to conduct projects consistent with the guiding principles of inclusive research. Research projects that are authentically inclusive plan for and strive to maintain meaningful engagement and decision-making power of co-researchers with intellectual and/or developmental disabilities. Additionally, inclusive research projects should address issues that are important to communities of people with intellectual and/or developmental disabilities, and should contribute to broader social change that improves the quality of disabled people's lives (Walmsley & Johnson, 2003). The ideal inclusive research plan is not simply to include people with intellectual and/or developmental disabilities as much as

possible, merely for the sake of inclusion. People with intellectual and/or developmental disabilities should be included as researchers leading or contributing to inclusive research because they bring value to the questions that are asked, the ways that research is conducted, and the impact of research outcomes (Walmsley et al., 2018). As described in this article, projects that are planned in diverse ways can strive to uphold these principles. We note that while planning is important, researchers should remain focused on purpose over pre-planning, and be prepared to adjust or abandon initial plans so that co-researcher engagement and social change remain central (Felner, 2020; Nind & Vinha, 2014).

In both of our inclusive dissertation research projects, we strove for trust, accessibility, and decision-making processes that facilitated shared leadership and authentic contributions to the processes and outcomes of the projects. However, our approaches differed by whom they were initiated, how co-researchers became involved, the roles of co-researchers, and the relationships among members of the research team. We also prepared differently for the outcomes of the research projects. As can be seen in our examples, contextual factors, such as funding availability, dissertation timelines, and IRB requirements, can impact how inclusive research projects are planned, and may limit the contributions and decision-making power of co-researchers with intellectual and/or developmental disabilities.

In both of our projects, relationships impacted all stages of planning. The centrality of relationships to inclusive research brings needed attention to the ongoing harms of the enduring exclusion of people with intellectual and/or developmental disabilities from society more broadly (Chalachanová et al., 2020). Unfortunately, persisting segregation of disabled people in our societies, especially from universities and research institutions, means that academically-trained researchers often do not have meaningful interpersonal relationships, let alone collaborative

partnerships, with people with intellectual and/or developmental disabilities in their communities. Similarly, because people with disabilities face barriers to forming and leading organizations, there are limited opportunities for partnerships with organizations of this type. Part of the work of furthering inclusive research is breaking down the cultural and structural barriers to the full community participation of people with intellectual and/or developmental disabilities in society that make truly mutual partnerships so difficult. Our experiences, and those of others (Loeper & Schwartz, forthcoming; McDonald & Stack, 2016; Shogren, 2023; Walmsley et al., 2018) suggest that in some cases, the strong relationships built during research may have the potential to help break down these barriers.

As we expect many inclusive research teams will relate to, planning inclusive research and conducting and disseminating that research can be two very different stories. Institutional policies and procedures can serve as systemic barriers to authentic engagement of people with intellectual and/or developmental disabilities in the research process (McDonald et al., in press; Shogren, 2023). In our examples, we can reflect on moments where institutional factors drove decisions that were not as collaborative as we had planned for. For example, [first author] had planned to meet with the co-researchers to collaboratively develop the second-round interview protocol, however, because there were limited grant funds left to compensate the co-researchers for meeting and because it could take weeks to receive the approved IRB amendment, [first author] wrote the second-round interview questions himself. Similarly, while [second author] intended to pay co-researchers for all time worked on dissemination, there was one dissemination opportunity that occurred after funding had concluded, which meant some co-researchers chose to engage in unpaid work. We wrestle with the tension of completing meaningful work with communities while working within time-consuming academic structures. Conducting our

projects within research institutions allowed us to access grants and gave us the time to work on these projects, but we wonder if these projects would have benefitted and moved forward more quickly if they occurred outside of research institutions.

Research teams planning inclusive research should discuss the benefits and drawbacks of limiting co-researcher involvement due to systemic barriers versus challenging those barriers. For example, we hope some research teams decide, based on their timelines and funding, to engage in education and advocacy to try to improve the accessibility of human subjects training or to pursue institutional approval of alternative, accessible training. We understand that many teams may decide instead to base team member roles on the existing human subjects training requirements. With open dialogue about the research partnership goals and potential barriers to collaboration, teams can collaboratively determine if and when to direct their resources toward breaking down these barriers. We encourage academic researchers to continue to identify barriers to inclusive research and to advocate for systemic changes that could improve inclusive research planning, such as extending grant application and funding timelines, supporting faculty service in community organizations, and expanding university hiring of co-researchers with intellectual and/or developmental disabilities.

Future Research and Limitations

This manuscript describes just two inclusive research projects. Other teams will have different experiences and perspectives, given their unique context(s), team members, and goals. Furthermore, we did not empirically evaluate how our planning processes impacted inclusive research processes or outcomes, nor did we include the voices or reflections of the co-researchers on our teams. As inclusive research becomes more common, we hope there will be sufficient resources and teams to conduct empirical research on the inclusive research planning approaches

that contribute to authentic inclusive research processes and further the goals of people with intellectual and/or developmental disabilities. For example, longitudinal observational designs could help identify how different approaches to initiation–by whom (i.e., by academics or people with disabilities) and when (i.e., before or after submission of grants)–influence decision making and power as research progresses. Other studies may evaluate how teams work together when co-researchers are or are not paid and how co-researcher recruitment is impacted by the availability of hourly vs. full-time/benefited jobs. These efforts should be conducted inclusively, so the voices and experiences of co-researchers drive procedures, targeted outcomes, and resultant actions.

In our short careers to date, we have already observed a growth of inclusive research and increased capacity of academic researchers and co-researchers with intellectual and/or developmental disabilities (Jones et al., 2020; O'Brien, 2022). The literature available to our projects was more extensive than that available to inclusive researchers before us, and we expect our own work may soon appear outdated as the science and practice of inclusive research continues to grow and realize its potential to bolster the power of people with intellectual and/or developmental disabilities. While existing principles, frameworks, and guidelines have been crucial in the development of our own inclusive research projects, we have both found that there cannot exist one universal framework for planning inclusive research, as the planning and adjusting of inclusive research projects should always reflect, by its very nature, the purposes and process of each unique research project. We found mentorship helpful in tailoring our approaches to our specific teams and projects. We encourage those new to inclusive research to connect with mentors and resources in the growing field of inclusive research, and for those with

experience in inclusive research to support the emerging community of inclusive research scholars.

Conclusion

Planning inclusive research projects involves thoughtful consideration of project initiation, team member characteristics and roles, relationships, accessibility, and outcomes. There is not a one-size-fits-all approach to planning inclusive research; many paths can lead to meaningful collaborations between academic researchers and co-researchers with intellectual and/or developmental disabilities with outcomes that meaningfully impact the lives of people with disabilities. We look forward to continued growth in the scholarship of inclusive research and practices that further break down systemic barriers to research engagement. We are hopeful that commitment to the principles of inclusive research, with support from a growing field of inclusive research mentors, will continue to contribute to a more inclusive and equitable society.

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August 1, 2023

To the editors and reviewers at *Inclusion*,

Thank you for taking the time to read and provide feedback on our manuscript INCLUSION-SPECIAL-ISSUE-S-23-00024 entitled "Planning Inclusive Research: A Comparison of Two Inclusive Dissertation Research Projects." We look forward to publishing this manuscript in the upcoming special issue of *Inclusion* and appreciate the reviewers' thoughtful comments, which we feel have improved the quality and relevance of our manuscript.

The table below outlines how the revised manuscript addresses the suggested revisions. All revisions are highlighted in yellow in the manuscript.

Reviewer Suggestion	Revisions
In the second paragraph of the manuscript, more detail would be helpful regarding previous planning frameworks. For example, the authors state that some projects plan with great specificity, while others plan more broadly. Firstly, please indicate if these projects are planned in partnership with people with lived experience. I assume so given the focus of the manuscript, but stating so directly will help the reader. Also, if possible, providing brief examples of the projects will help with specificity. (R1)	We have clarified that the frameworks referenced are about inclusive research broadly, and not specific to planning. We gave an example of how the Frankena et al. (2019) consensus statement includes inclusive research attributes relevant to planning. Given the length of this manuscript, we are not able to describe the frameworks in detail. We have also clarified that planning may occur with or without people with disabilities.
In terms of organization, on page 5, the authors list the five sections they use to organize the description of the manuscript. Yet, little justification is given for using this structure. The justification is woven throughout the Comparing Planning Approaches section, though. I suggest the authors introduce the components of planning inclusive research - and move the detailed description of each of these components - in the introduction to provide a firm grounding in the framework. (R1)	We experimented with presenting the justification of the five planning components at the beginning of the Comparing Planning Approaches section. We felt that this separated the literature justifying these components from our comparisons, thus making the manuscript more difficult to follow. We have added statements on pages 5 and 7 explaining that each section first justifies the planning component with IR literature, then presents a comparison of our projects. We feel this organization justifies the structure of the paper, while keeping related sections together.
On p. 1, in footnote 2, I wonder about acknowledging terminology will continue to change and evolve over time. It seems that current distinctions may not always be	We have revised the footnote to acknowledge ever-changing terminology.

needed, warranted, or the same. I wonder if it is important to acknowledge this in some way here or elsewhere. (R2)	
On p. 3, end of first paragraph, are the consensus statements and practice guidelines to guide academic researchers as they embark on research partnerships or inclusive research. Do these terms mean the same thing? (R2)	We have revised the text to clearly refer to "inclusive research partnerships."
Can you elaborate on the statement on p. 4 about the Walmsley paper about providing "traditional research training." How does this author define this? (R2)	We have clarified that Walmsley and colleagues referred to training in traditional scientific methods and processes.
Can you highlight reasons why as noted on p. 8, in the U.S. it is less common for inclusive research teams to form independent of research funding and collaborative pursue funding. What are the barriers? Also, do teams evolve? Can they start one way and then grow in a different way? (R2)	We feel that these questions are appropriate for deep discussion in a different manuscript. We have provided 3 examples of teams working independently of funded research projects in text. However, the *why* of this is not something we can explore in depth. We have revised the sentence to frame this as an alternative approach and de-emphasize international differences. We do not have the space to further address all the reviewer's questions here.
For the first author and initiating, do you think the co-researcher would have been able to identify an academic researcher to partner with if not for the first author's relationships to the community and the work that came to drive the project? I think the role of relationships that evolve is a thread in these examples. (R2)	We have added a statement acknowledging that if the co-researcher did not have this relationship with the first author, it is unlikely that she would have decided to conduct a study or looked for an academic research partner.
Can you describe further how the second author then identified people to be a part of their research project? Were there linkages to the community that identified these issues already in place to support initiating? What about letters of support for the funding application if a focus was on inclusive research? (R2)	We have added details about how letters of support were provided prior to submission and how these relationships and commitments were used to help identify co-researchers.

I agree with the point on recruiting on p. 11-12, but if people have not had experience with research, now can you assess alignment and ensure it is a good fit? (R2)	The text here notes that recruitment is based on interest in a topic and/or similar experiences—not experience with research. We have added a phrase to emphasize that research may be a new experience. We later provide an example of how the second project used an approach to introduce research during interviews.
How is compensation defined by inclusive research teams? Are these full, paid roles, consulting roles, etc.? How are those decisions made? (R2)	We briefly cite literature on the importance of fair compensation for co-researchers. Then, we can only comment on this for our specific projects. We have provided detailed information about how we paid our team members. We have revised language about "salary" to make it clear that we paid individuals on an hourly basis. We have described in text how we made decisions about the amount of time co-researchers worked and how we selected hourly rates.

This is not something that we can further comment on broadly based on wide institutional and team variability. |
| What are the pros and cons of not fully involving co-researchers because of systemic barriers (e.g., IRB training)? What systemic factors facilitate and create barriers to inclusive research and what is the role of academic researchers in breaking those down? (R2) | In the discussion, we describe how research teams can decide whether to challenge systemic barriers and give an example. We encourage academic researchers to advocate to break down these barriers. |
| I'd like to see more depth in the discussion of contextual factors, particularly systemic factors at universities or in the research enterprise (e.g., journals, university structures/hiring, etc) that can impact inclusive research beyond just funding and timelines. For example, in relationship building what is the role of university and professional organization structures? Are changes needed in these systems and in policy? (R2) | In the discussion of contextual factors, we give a few examples of systemic changes that could improve inclusive research planning. |

On. P. 17 is a heading missing to support transitioning back to discussing the RISE Up Project or perhaps this is a summary/synthesis? (R2)	We have reorganized the text to make it clear that this a summary paragraph, rather than specific to one project.
On p. 21-22 can you provide a bit more detail on if the 2nd author's IRB had experience with inclusive research or if this was an easy process to get them to accept a modified, accessible research ethic training. Further, was this something developed by the author or is this something that can be cited and used by others? (R2)	We have added additional detail about the development of the training and the IRB approval process.
Also, what might be some questions that would or could be asked in empirical research on inclusive research to advance practice? (R2)	We have added a few potential research questions.

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