Inclusion

Collaboration with Researchers with Intellectual/Developmental Disabilities: An Illustration of Inclusive Research Attributes Across Two Projects
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Abstract

Researchers have implemented inclusive research for over thirty years. This paper describes how two research projects collaborated with researchers with disabilities and aligns the description with four attributes of inclusive research developed by a consensus of international experts with and without disabilities. The first project, the Person Experiences Interview Survey (PEIS) Workgroup, reviewed and revised items for a self-report survey of mental health service experiences. The second project describes the peer-led implementation of the Self-Determined Career Design Model (SDCDM) intervention. Four factors facilitated or were barriers to the projects' alignment with inclusive research attributes. First, relationships enhanced capacity to engage in meaningful ways. Second, balance between consistency and adaptability promoted engagement. Third, long term capacity was enabled by ongoing engagement and peer mentorship. Fourth, time and funds impacted inclusive implementation. Engaging researchers with disabilities meaningfully enhanced the research process and products.

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Introduction

In response to Walmsley's groundbreaking publication (Walmsley, 2001) articulating the

value of inclusive research, health, education, policy, and disability research has adopted the

approach to conduct research in partnership with people with intellectual and developmental

disabilities (IDD) (Garratt et al., 2022; O'Brien et al., 2022). Inclusive research operationalizes

the value of "nothing about us without us" to leverage the expertise that derives from the lived

experience of disability (Nicolaidis et al., 2019; Walmsey & Johnson, 2003; Walmsley &

Johnson, 2003). Collaboration with people with IDD in the implementation of research enhances

the accessibility, relevance, and impact of research findings and products (Beighton et al., 2017;

Walmsley et al., 2018). People with IDD have been historically excluded from participation in

the research process for multiple reasons including inaccurate assumptions regarding their ability

to engage in research activities and a de-valuing of their lived expertise (O'Brien et al., 2022). In

contrast to this exclusion, inclusive research or related approaches including participatory

research, community-based participatory research, and action research, provides an opportunity

to demonstrate the potential and impact of people with IDD within our field as well as to broader

society.

Despite the potential benefits and over thirty years since the onset of inclusive research,

the US lags behind in this practice, with fewer published examples of inclusive research

compared to the United Kingdom (as previously identified in reviews) and Australia

(Chalachanová et al., 2021; Di Lorito et al., 2018; Frankena et al., 2015). Further, journals

affiliated with the AAIDD have been reported to publish fewer inclusive research studies than

journals affiliated with other national and international IDD professional associations (O'Brien et al 2022). This highlights the need to increase the field's capacity to conduct inclusive research in the United States (Shogren, 2022).

There is a wealth of resources that demonstrate how to conduct research in collaboration with people with IDD, many developed in partnership with people with IDD (Frankena et al., 2019; Nicolaidis et al., 2019; RDI Network, 2020; Strnadova et al., 2022). The Fankena et al. (2018) guidelines are unique, as they were developed by a group of international inclusive health research experts, including 17 experts without disabilities and 40 experts with disabilities. The guidelines were part of a consensus statement on inclusive health research that was developed through a review of Delphi study results about the same topic, a roundtable discussion, and iterative written feedback(Frankena et al., 2018). .

Frankena and colleagues' (2018) consensus statement included the delineation of eight attributes of inclusive health research; four of the eight pertain to the implementation of a study and are described in Table 1 (other attributes pertain to the design of inclusive studies, and dissemination, and are not the focus of this manuscript). This paper is focused on implementation of research, thus we will exclusively focus on the four attributes that guide implementation of research. The first, Facilitating the Process, ensures collaboration "by ensuring researchers with intellectual disabilities' meaningful inclusion through planning, discussion and decision-making" (Frankena et al., pg. 5). Dealing with Practicalities, the second, directs the team to prepare for the logistical elements of research collaboration. This includes ensuring all members have the transportation, time, and support needed to engage in a meaningful way. The third, Generating Data, includes the process of planning and completing accessible and confidential data collection. The fourth, Analyzing the Data, includes training and other preparation for analysis

as well as accessible approaches for analyzing patterns in qualitative or quantitative findings.

The consensus statement details a set of criteria that operationalize each attribute (see Table 1).

The aim of this paper is to describe how two projects implemented research in

collaboration with people with IDD, using the Frankana and colleagues (2019) attributes as a

framework for structuring the examples. Using the attributes as a common framework illustrates

how collaborative research can be implemented to meet each study's unique context and aims,

while still aligning with attributes deemed essential for inclusive research.

Using Inclusive Research Attributes to Describe Projects

This is a retrospective evaluation of two research projects, with each research team

process as the unit of analysis (Hyett et al., 2014). "Real life" descriptions of the research

implementation process can advance the understanding of inclusive research with people with

IDD, while remaining relatable to the reader (Stake, 1978). To complete an in-depth and rich

description of each research team's process, we used meeting agendas, meeting slides and

handouts, and minutes/notes created during each respective process. These activities were then

mapped against each attribute as defined in Frankena and colleagues (2019) aligned with the

implementation of inclusive research (described previously): (1) Facilitating the Process, (2)

Dealing with Practicalities, (3) Generating Data, and (4) Analyzing Data. The specific ways in

which each team facilitated engagement in the research process are described below and aligned

with the four attributes and corresponding criteria in Table 1. As a final process, we identified

factors across projects that facilitated or were barriers to the projects' alignment with inclusive

research attributes.

In keeping with the need for transparency of the authorship process in inclusive research,

two research teams partnered in the writing of this manuscript, including researchers with

disabilities (Strnadová & Walmsley, 2018). To create this manuscript, two researchers without disabilities (Kramer, Dean) identified the structure and outline. Next, each project separately generated their critical evaluations through a team writing process. To generate the discussion, each project identified important conclusions and recommendations, which were integrated by the first author and edited by all co-authors. Each project has self-identified the specific language used to refer to people with IDD on their research team.

Implementing Inclusive Research: Two Examples

Study 1: Development of the Person Experiences Interview Survey (PEIS)

      The Context of the Study. Patient-reported experience and outcome measures have been widely adopted in the mental health care sector to evaluate quality and effectiveness of care (Cella et al., 2015; Terwee et al., 2018). Although people with IDD and mental health needs (IDD-MH) are more likely to interface with multiple service systems and are at greater risk of emergency mental health service use (Kalb et al., 2016; Kramer et al., 2019), there is a lack of self-reported measures of service experiences that are accessible and relevant for people with IDD-MH. The Person Experiences Interview Survey (PEIS) (J. B. Beasley et al., 2023) was developed as part of a larger study comparing the effectiveness of in-person and telehealth mental health services within START (an acronym for Systemic, Therapeutic, Assessment, Resources, and Treatment) sites across the United States (J. Beasley et al., 2018; Kalb et al., 2019). The PEIS was adapted from the FEIS (Family Experiences Interview Survey), a family caregiver survey already used by START. The research team determined that a lack of direct feedback from service users was a major obstacle in learning about service experiences and outcomes and worked with the author of the FEIS to establish parameters in which the PEIS could be developed. Designing parallel measures would enable the research study to the extent to

which mental health providers and services were accountable, appropriate, and accessible for both people with IDD and their caregivers.

The development of the PEIS was an interactive, multi-step process that included measurement and clinical experts, collaboration with individuals with disabilities, and gold standard methods for establishing content validity of tools such as cognitive interviews and focus groups (Terwee et al., 2018). A central component to this development process was collaboration with the "PEIS workgroup," (described below). Prior to the workgroup formation, measurement and clinical experts who were members of the project's Leadership Team drafted a set of initial PEIS items based on each FEIS item and a Likert scale. The PEIS workgroup then engaged in a series of meetings over 2.5 months to review and revise the initial items; all members were compensated for their time. The workgroup had two goals: 1) to review each PEIS item for clarity and accessible language (e.g., avoiding long sentences and complex words), and 2) provide feedback on the relevance of the evaluated mental health service experiences for people with IDD. Items were revised and re-reviewed by the PEIS workgroup until no additional concerns were identified.

Team Members. The PEIS workgroup included four researchers with a variety of different experiences of disabilities and all with mental health service experiences, including experts with Intellectual Disabilities and Autistic experts (with and without intellectual disabilities). Two researchers with disabilities (including Peace Urquilla) had previously worked with the study's Principal Investigators on two previous projects, over a period of six years. They were already involved in this project as members of the Engagement Team, and Peace Urquilla was also a member of the research Leadership Team. The Engagement Team includes individuals with IDD-MH, family members, START providers, and researchers who meet bi-

weekly to collaborate in the development of all research study activities and materials. The two

other experts on the PEIS workgroup were individuals identified through the PI's national

professional networks. One expert was an experienced leader of his state's self-advocacy groups.

The other had experience creating short videos and documentaries about his daily life as a person

with a disability, with a focus on rights such as supported decision making. These two members

served as members of the research team's Advisory Council for approximately 10 months, and

had engaged in three Advisory Council meetings, prior to accepting the invitation to collaborate

in the PEIS workgroup.

The PEIS workgroup was facilitated and supported by the primary research study staff,

including the co-PI (Kramer) and an engagement coordinator. Both had clinical expertise in IDD

and/or mental health supports. The co-PI had over 15 years of experience collaborating with

people with IDD in projects, and the engagement coordinator partnered with two members of the

workgroup in a prior project. Communication between the PEIS workgroup and the Leadership

Team was fluid and ongoing. The team PI (Beasley) and other co-PIs met weekly with Kramer

and Peace Urquilla, who acted as liaisons and reported group progress and feedback. This

mechanism integrated the efforts of the workgroup into the full study design. See Table 2 for a

summary of the team roles

Attribute 1: Facilitating the Process. Prior to meeting, we established a weekly time

that was convenient for everyone's schedule. The group wanted to meet each week at the same

day and time, so the schedule was easy to remember. The meeting schedule was based around

the availability of the members who were in different time zones and had other work and

personal responsibilities. When workgroup members could not attend meetings, we scheduled

individual make up meetings when possible. We met using video conferencing (Zoom™),

because it was the only way to bring our national workgroup together. However, this was hard for one member of the workgroup, who was "zoomed out." We acknowledged this challenge and kept each meeting to one hour to limit screen fatigue.

Our first meeting together focused on building relationships and ensuring a common understanding of our purpose. Prior to the first meeting, we asked all members to complete the VIA Character Strengths Survey (Littman-Ovadia et al., 2021), which draws from positive psychology principles. During the first meeting, each member shared their top three character strengths. Focusing on the strengths each member brought to the work at the beginning of each meeting reminded us of our unique and shared contributions to the common goal. These strengths were listed on all future meeting agendas as a reminder each week. The workgroup also discussed the importance of eliciting the perspectives of people with IDD about their experiences with mental health services and providers, and how the availability of an accessible measure could enhance quality of care. This discussion was facilitated by a video recording of an advocate who identified as a person with IDD and mental health service experiences who described their perspectives on why a tool like the PEIS was needed. The discussion provided the team with a shared framework of the purpose of the project.

To prepare for each subsequent meeting, members received an email and agenda one week, one day, and one hour before each meeting. The agenda specified what to "read, do, and think" before each meeting, and listed the PEIS items that would be reviewed during the meeting. Two workgroup facilitators without disabilities met with members prior to the meeting, when needed, to review the agenda and prepare for the meeting. All meeting materials used plain language and consistent formatting to reduce cognitive load. For example, the meeting email and agenda included the meeting date, time, zoom link, and directions to prepare for the

meeting in an easy-to-read table. During meetings, draft items were presented one at a time, next to the Likert scale with visual cues, on a PowerPoint™ slide using the videoconferencing share screen.

To provide an opportunity for team members to build relationships, each meeting began with an activity called 'question of the week.' While the research team facilitator generated the icebreaker question for the first three meetings, a member of the workgroup facilitated the activity with a question of their own for the remaining six meetings. Members took turns coming up with their own question of the week to ask at the upcoming meeting. Examples included "What is your favorite movie?" and "What was your favorite summer activity growing up that you still do now?" The questions took about 10 minutes to discuss and gave team members the opportunity to learn about each person's interests, background, and life experiences.

Developing items for measures requires one to take the perspective of others to consider how respondents may interpret the question. Working as a group can enhance this process. If each member contributes their own interpretation of an item, the group can identify if there is a shared understanding that matches the intended item meaning, or if certain words or phrases contribute to a poor item clarity. However, accounting for the perspectives of others or articulating how one understands a question is an abstract task which may be inaccessible for some people with IDD. To make the process of reviewing items accessible, we used a two-step process. First, members viewed the PEIS question and the prompt "What Likert response would you pick for this question, and why?" Each group member responded individually to each question using the Likert response scale. Responses were gathered anonymously using the "poll" feature in the video conferencing platform, allowing all workgroup members to contribute. After all responses were compiled, each member was provided an opportunity to share how they rated

each item and why. Second, to provide targeted feedback about the clarity of the item, members

viewed the PEIS question and the prompts "Do any words need to be added or changed?" and

"Think of a visual or picture example for this question." Still, the use of multiple prompts felt

cumbersome as some members provided similar feedback for the first and second set of prompts.

The PEIS workgroup Facilitators removed the prompt "think of a visual, or picture example" to

reduce the amount of time needed to review each item and reduce confusion.

 During the item review process, it was observed that some members, in their enthusiasm,

contributed at length in these discussions, while other members only shared when explicitly

asked directly. After a few meetings, one team member suggested privately with the PEIS

workgroup facilitator that she was unsure when and how to interject her ideas. She suggested

members use the "raise hand" feature to indicate they wanted to share. This cue would remind

members to give other people the opportunity to share, rather than always being the first to jump

in. This new communication process was added as a reminder slide to the beginning of each

remaining meeting and implemented successfully to provide equitable opportunities for

engagement.

 During the final meeting, the group celebrated their accomplishments including the

number of items reviewed, the number of meetings, and priorities identified by the workgroup.

The members also identified and celebrated the strengths each member contributed to the

development process. In a strength-spotting exercise informed by positive psychology principles,

members took turns sharing how each team member activated their strengths to positively

contribute to the process. For example, one member activated his strength of "honesty" to

provide honest feedback about wording that was confusing or difficult. Another member

activated their strength of "leadership" to help other members learn how to critically evaluate

questions by sharing their thought process to designing accessible questions. This exercise provided the group with closure for the workgroup process.

Attribute 2: Dealing with Practicalities. When scheduling and coordinating meetings, we communicated directly with each member, providing calendar invitations for each scheduled meeting. One member asked the PEIS workgroup facilitators to cc: his family member on emails, but direct contact was made with the family only once to arrange compensation. All workgroup members attended and engaged over Zoom without direct support. While most members attended most meetings from a private location in their home, the flexibility of video conferencing allowed one member to attend from a variety of community locations according to his schedule including a coffee shop, train station, and even a commuter ferry.

Adhering to a project timeline and adapting the timeline in response to emerging needs and findings is a crucial component of research project management. The PEIS workgroup initially scheduled five meetings. However, to provide sufficient time to review all 21 items with full input from all team members, and to follow up on subsequent item revisions, the schedule expanded to nine group meetings. While this extended the deadline for the completion of the PEIS, the Leadership Team valued the input of the workgroup members over meeting the initial timeline. The Leadership Team also secured additional funds to increase the compensation of workgroup members. About six months later, members met with PEIS workgroup facilitators to provide feedback on a PEIS instructional video. Finally, after the completion of interviews and focus groups to evaluate the content validity of the PEIS, the workgroup members reviewed findings and the final set of PEIS items.

Attribute 3: Generating Data. The original design and methods to establish the content validity of the PEIS items were developed by the research team during the grant application

process. However, members of the workgroup made significant contributions to the design of the administration process of the PEIS. While reviewing and revising the PEIS items, the workgroup identified the following administration priorities: 1) clearly define mental health providers and services, 2) ensure the respondent understands how their responses will be used and that their perspective matters, and 3) provide accommodations to allow all people to provide their perspectives using the PEIS. The workgroup also provided feedback on the visual cues, including colors and symbols, used with the PEIS Likert response scale. These administration protocols were used in data collection. There was an impact beyond data collection, as the directions were incorporated into the PEIS administration manual for use in clinical practice (See Table 3).

Attribute 4: Analyzing Data. The entire workgroup was not involved in analysis of content validity data due to time and resource constraints, including time of research personnel to support the team, budget to continue to pay workgroup members for their time, and time constraints to finalize the instrument for the implementation of the comparative effectiveness trial. However, one member (Peace Urquilla), as part of their other responsibilities and role on the Leadership Team, coded focus group responses to evaluate the relevance and comprehensiveness of the items. They previously participated in 1-month long team training on qualitative data coding and had experience coding other qualitative data.

While coding family member responses, the team member was surprised and initially upset to find that some focus groups with informants contained implicit biases regarding people with disabilities, particularly people with IDD. As a self-advocate who has often been confronted with these implicit biases from others in their personal life, the team member found it difficult to engage with negatively biased focus group responses. While sharing this experience during a

team meeting, another team member noted that responses from a second informant group were more neutral. The team members traded analytical assignments, so the researcher with disabilities could continue to participate in data analysis without confronting additional activating material, and completed the rest of the analytical process without further barriers.

Study 2: The Self-Determined Career Design Model (SDCDM) via Telehealth

Context of the Study. The Self-Determined Career Design Model (SDCDM) is an intervention that supports people to set and go after career related goals and reflect on their progress toward their goals (Shogren et al., 2021). It is a career-focused version of the Self-Determined Learning Model of Instruction (SDLMI), which is an evidence-based practice in transition instruction (National Technical Assistance Center on Transition, 2016). The SDCDM is a three-phase model in which a facilitator supports a person to (1) set a goal, (2) develop an action plan to achieve the goal, and (3) reflect on progress toward the goal (see Dean et al., 2019, 2022 for more information about implementation of the SDCDM). Facilitators support people to work through a problem solving sequence consisting of 12 Person Questions (four Person Questions per Phase). Facilitators use Facilitator Objectives and Employment Supports that were designed for each Person Question and serve as a road map for facilitators supporting people to answer the Person Questions. In this project, facilitators without and with the lived experience of intellectual and developmental disabilities implemented the SDCDM over telehealth to support adults with intellectual and developmental disabilities to set and go after career related goals. Facilitators met with participants weekly for one-hour SDCDM sessions for six months. Facilitators met bi-weekly with a coach, who had extensive experience implementing the SDCDM. Table 4 describes the different roles of people engaged in the SDCDM project. In the

following sections, we will describe the training and support procedures that were used to support facilitators with lived experience to enhance fidelity of implementation.

Team Members. The research team consisted of project staff and facilitators. Project staff included the Principal Investigator, who also served as the coach for facilitators, who had extensive knowledge of SDCDM implementation in community contexts and did not have lived experience of intellectual disability, a co-PI with extensive knowledge of SDLMI implementation and did not have lived experience of intellectual disability, a postdoc who had experience facilitating the SDCDM and identified as neurodivergent, and one SDCDM facilitator who had lived experience with a developmental disability.

All facilitators were employed by community organizations serving youth and adults with intellectual and developmental disabilities, and included five facilitators with lived experience of an intellectual and/or developmental disability, and five facilitators who did not have lived experience of an intellectual and/or developmental disability. Three facilitators with lived experience had extensive experience as peer supporters for people with disabilities enhancing self-advocacy skills and also had experience obtaining and maintaining employment. The remaining two facilitators with lived experience had personal experience obtaining and maintaining employment, however, did not have experience as peer supporters. All facilitators without lived experience were trained to implement evidence-based practices in either educational (e.g., teachers) or employment contexts (e.g., job coaches). Throughout training and implementation, facilitators with lived experience offered feedback on training and implementation materials, which were continually refined based on feedback. In the description below, to differentiate between facilitators with and without lived experience of an intellectual and/or developmental disability, we will refer to facilitators with lived experience of an

intellectual and/or developmental disability as "facilitators with lived experience" and facilitators

without lived experience of an intellectual and/or developmental disability as "facilitators

without lived experience." Training and implementation processes were generally designed to be

inclusive of facilitators with and without lived experience, so at times we refer to "all

facilitators" to indicate facilitators with and without lived experience.

       Attribute 1: Facilitating the Process. To prepare for the process of implementing the

SDCDM (see Table 5 for overview), the team needed to adapt resources previously created and

used by researchers without the lived experience of disability. This included session descriptions,

PowerPoint [PPT] slides that supported facilitators to teach key concepts, and session activities

designed to engage participants in meeting session objectives. To adapt the materials, two project

staff with extensive experience implementing the SDCDM and one staff member with lived

experience co-adapted implementation materials to be accessible (e.g. use plain language,

inclusion of sample scripts). Further, during training and coaching sessions, project staff with

experience facilitating the SDCDM reviewed implementation materials with facilitators with and

without lived experience to discuss the intent of the materials and get feedback on the

accessibility of materials. Facilitators with lived experience indicated that the existing session

descriptions were too long (5-6 pages) and that the scripts were hard to follow. This process led

to the development of new session descriptions that were one-page in length. Further, rather than

the originally developed sample scripts to teach concepts, facilitators with lived experience

preferred a notes page that had an image of each PPT slide and room for them to write or type

their own script for each session. Through the inclusive processes described above, facilitators

with lived experience were supported to meaningfully contribute to the implementation phases of

the research project.

Prior to implementing the SDCDM intervention, all facilitators needed training to learn the key components of the SDCDM and prepare for facilitation. Following best practice in implementation research, project staff also led bi-weekly coaching sessions to enhance fidelity of intervention delivery (Hagiwara et al., 2020). As noted above, training and coaching procedures were originally designed based on previous research using the SDCDM and SDLMI. Training for facilitators consisted of three hours of asynchronous remote training where facilitators watch videos teaching the main components of the SDCDM. Videos were divided into 30 minute segments to promote accessibility. This was followed by two hours of synchronous remote training where an expert in SDCDM implementation modeled an SDCDM session, all facilitators practiced facilitating an SDCDM session, and all facilitators planned for their implementation.

Throughout the six-month implementation timeline, all facilitators met as a group with an expert SDCDM coach who led sessions (called coaching sessions) designed to enhance SDCDM fidelity. Facilitators with lived experience also met individually each week with a trained SDCDM facilitator without lived experience to prepare for each session (called prep sessions). The trainings and coaching sessions were led by an SDCDM coach (Dean) who had extensive experience facilitating the SDCDM and who did not have lived experience of disability. However, facilitators with lived experience co-developed the processes by which the training and coaching were delivered. First, all facilitators and the coach agreed that coaching sessions would occur every other week; sessions were scheduled at a convenient time for all team members and were conducted remotely using teleconferencing software since members of the research team lived in different states. Coaching sessions used the same structure for each meeting to support facilitators with lived experience to prepare for and fully engage in each part of the meeting. The first 5-10 minutes of each coaching session was unstructured time where the research team could

get to know each other better. One facilitator with lived experience emerged as an organizer of this time by coming with questions to ask other team members. The next 20 minutes consisted of reporting, where each facilitator would share their experiences facilitating the SDCDM.

The final component of the meeting was problem solving. Items to discuss during the problem-solving part of the meeting were developed in two ways. First, as facilitators reported about their experiences, when facilitators described a challenge they were facing with their facilitation of SDCDM sessions, the coach would ask reflective questions to support critical thinking about the problem during the problem-solving session. For example, if a facilitator was challenged by a situation where a person's family member was answering questions for the person, we may ask "How would you ask a friend to support your decision making?" If the facilitator indicated they wanted to talk more, the coach would add the issue to the list of things to discuss during the problem-solving session. The research team would also identify items for problem solving based on observations of recorded SDCDM sessions.

An example of a topic that was discussed during a problem-solving session was related to pacing of the sessions. A facilitator with lived experience canceled an SDCDM session one week because they were on vacation and then tried to complete two sessions the following week by moving quickly through session materials and not leaving enough time for the participant to discuss important topics. In this case, the team reassured the facilitator that it was ok to miss a session and then supported the facilitator to identify strategies for making up missed sessions (e.g. conducting two SDCDM sessions in one week), and decide the best option for them and their participant. The facilitator's supporter would then follow up in their weekly planning meeting to plan for implementing the strategy, including discussing the strategy with their participant.

Early SDCDM coaching sessions mainly focused on problem solving about facilitation, such as how to best use the PPT slides and how to document sessions and how to best engage participants in sessions. Questions were primarily addressed by the coach and the facilitation supporter. As time went on and facilitators with lived experience gained experience with facilitation and became comfortable with the group, problem solving discussions became a group discussion, with facilitators with lived experience sharing their experiences to support other facilitators in developing new strategies for facilitation. This created a dynamic learning culture where everyone felt comfortable sharing their experiences to support others.

Attribute 2: Dealing with Practicalities. The SDCDM via Telehealth project staff communicated directly with all facilitators to coordinate meetings. One facilitator without lived experience of disability also served as the primary coordinator for all facilitators with lived experience, so when coordination emails were sent, this facilitator followed up individually with all facilitators with lived experience directly to ensure changes in scheduling worked for each facilitator. As noted earlier, meetings (both SDCDM sessions and coaching meetings) were conducted using teleconferencing software. While all participants had experience using the teleconferencing software, facilitators gathered in person for the first training session to practice using the software. Practice during the first training session consisted of each facilitator connecting to the sessions, sharing their screen, and muting/unmuting their microphone. At the first meeting, the team also discussed the timeframe for meetings and decided to meet every-other week for one hour for coaching sessions.

To adhere to the project timeline, the Principal Investigator created a six-month implementation timeline that detailed the SDCDM Person Questions to be covered each week. At each coaching session, all facilitators discussed their progress with implementation, and if

needed, the team would discuss changes to the project timeline to meet the scheduling needs of

facilitators and participants. However, the project needed to adhere to a strict timeline and while

excess time was budgeted into the timeline, it was not always possible to extend timelines.

Further, all implementation materials were added to a website where facilitators could

access all materials needed for the session. The website used images to display materials and

organized content by SDCDM session, which corresponded to the project timeline, so needed

materials could be quickly identified. Facilitators with lived experience reported that these

features made the site easy to navigate and find the materials they needed. Some facilitators with

lived experience indicated they preferred to use print materials for their preparation, so SDCDM

session booklets were created that contained all implementation materials.

Attribute 3: Generating Data. During implementation of the SDCDM intervention,

facilitators with lived experience were engaged through two primary methods – coaching

meetings and the SDCDM sessions they facilitated. During coaching meetings, the team,

including project staff and facilitators with and without intellectual disability, made decisions

about material refinement, timeline adjustment, and strategies to support participants (if needed).

For example, facilitators with lived experience stated that the scripts created by the research team

were not written how they would talk, and that they preferred to create their own script. The

team then worked with the facilitators to create a notes page for each PPT slide, so facilitators

could create their own script for each slide. During the SDCDM sessions, all facilitators

supported participants to work through the SDCDM. Both methods were designed to be inclusive

and to support meaningful engagement by facilitators with lived experience.

Participant data in this study was collected via an online system and was coordinated by

project staff at KUCDD. All facilitators distributed individual links to the assessments for

participants, but were not directly involved with data collection. This decision was made by the

team because of the challenges inherent in completing IRB trainings that were not designed to be

accessible for people with intellectual and developmental disabilities. All facilitators did receive

training in confidentiality to ensure privacy of participants during coaching sessions.

Facilitators with lived experience played an important role in supporting participants to

set goals and track progress. This is an important component of the SDCDM process. All

facilitators received two hours of training in goal attainment scaling. During this training,

facilitators learned about the components of SMART (Specific, Measurable, Achievable,

Relevant, and Time-bound) goals and learned a systematic approach used in the SDLMI and

SDCDM to support participants to set SMART goals. Facilitators then learned a coaching

strategy designed by the research team and integrated into SDCDM procedures to support

participants to create a goal attainment scale based on the SMART goal. Facilitators then

supported participants to set SMART goals and develop a rating scale to track progress using

goal attainment scaling. Supporters during planning sessions reinforced the learning about

SMART goals and practiced facilitating conversations about goal setting with facilitators. Staff

at KUCDD also reviewed all goal attainment scales for quality. If scales needed adjustments, for

example, if the scale did not align with the measurable components of the goal, KUCDD staff

would explain multiple ways to make the adjustments so the facilitator could decide the best

alternative from their perspective. The facilitator would then discuss the changes to the goal with

the participant. Through this process, the original intent of the goal was maintained, for example

if the goal was focused on applying to jobs in a particular field, the goal kept that focus. Quality

adjustments consisted of ensuring the goals were specific and measurable.

Attribute 4: Analyzing Data. At the time of this writing, data collection for this project is ongoing and data has not yet been analyzed. Data analysis will be led by trained methodologists at KUCDD, however, the KUCDD staff does plan on discussing de-identified results with facilitators. Our plan is to discuss overall findings from the data analysis and learn from facilitators with lived experience why they think we might see the patterns that we see. We believe this process will yield discussion points that are more meaningful to the lives of people with intellectual and developmental disabilities.

Discussion

Across the two projects, we identified four factors that impacted either facilitated alignment with the consensus attributes outlined in Frankena and colleagues (2019), or in some instances, were barriers to the full attainment of all inclusive research attributes. They are:

- Relationships with partners enhanced team capacity to engage in meaningful ways,

- A balance between consistency and adaptability promoted engagement for people with IDD,

- Long term capacity for inclusive research was enabled by ongoing engagement and peer mentorship, and

- Time and financial constraints impacted collaboration in all phases of implementation.

Relationships with Partners Enhanced Team Capacity to Engage in Meaningful Ways

Positive and open relationships facilitate team success, and this is equally true in research (Schwartz et al., 2020; Schwartz & Durkin, 2020). For the PEIS workgroup, taking the time to build relationships focused on strengths, as with the use of the character strengths survey and question of the week, enhanced our overall sense of community and ability to collaborate as a workgroup. This allowed the experts both with and without disabilities to become well-

acquainted with each other's working and communication styles, accommodation needs, and importantly, the ethos or philosophy that drives the work. Finding commonality in this ethos and being able to rely on both it and each other over time contributed to helping experts with disabilities to feel empowered to contribute not only to the content of the work, but to the leadership and facilitation of the workgroup itself. The team's flexibility and commitment to supporting fluid or emergent access needs, as in the situations with speaking up during meetings, or addressing a sense of discomfort during data analysis, demonstrates how inclusive research can be operationalized to empower researchers with disabilities to not only be part of the work, but to be assured that researchers with disabilities truly belong. For the SDCDM via telehealth project, longstanding relationships with Imagine Enterprises helped conceptualize the training and support processes established for facilitators with lived experience. This work centered the experiences and preferences of people with lived experience in the designing of research processes established to support fidelity of implementation of the SDCDM and promote positive self-determination and career outcomes for participants. These examples operationalize the value that inclusive research isn't just about making sure people with IDD are in the room, but are really centered, empowered in group discussions and decision-making, and a sense of connection & belonging (Schwartz & Durkin, 2020).

A Balance Between Consistency and Adaptability Promoted Engagement for People with IDD

Consistency and predictability in both time & meeting routine are accommodations that support access and promote engagement for people with IDD. This is well documented in the inclusive literature (Frankena et al., 2019; Nicolaidis et al., 2011, 2019; Schwartz et al., 2020), but these projects demonstrate that these routines can be operationalized in a range of research contexts including groups that work virtually. For example, both teams kept a consistent meeting

schedule, and relied on materials like meeting agendas or intervention implementation materials that used consistent design and format standards. While consistency enhances accessibility, it is equally important to be responsive to the needs of the team that shift over time; as the team builds capacity, different types of supports and access strategies are needed (Schwartz et al., 2020; Schwartz & Durkin, 2020). For example, in the SDCDM via telehealth project the coaching sessions shifted from facilitator led to discussion-based problem solving as team members gained skills and confidence. In the PEIS workgroup, the timeline was expanded in response to the groups' approach to providing feedback to ensure all felt heard. This responsiveness is possible when ongoing critical reflection and evaluation of the implementation process is combined with open communication with research partners (Frankena et al., 2019).

Long Term Capacity for Inclusive Research was Enabled by Ongoing Engagement and Peer Mentorship

Research can require specialized training and skills, and inclusive research scholars have debated the role of formalized research training for team members with disabilities, and the consensus guidelines used in this manuscript reference the importance of training and orientation (Frankena et al., 2019). Some scholars have stressed the need to build research skills so that people with disabilities have the capacity to be engaged in a way that is rigorous and knowledgeable (Embregts et al., 2018; Flood et al., 2013; Strnadová et al., 2014). Conversely, others highlight the expertise derived through lived experience, with a "distinct value" (Walmsley et al., 2018, pg. 751) that only people with disabilities can provide (Beighton et al., 2017; Bigby et al., 2014). In both projects, the research team included people with IDD in different roles with different responsibilities in the overall project. Some members with prior research experience had the capacity to engage in a broader set of research activities that

required an understanding of the full research study including planning, mentorship and

supervision of other team members, and analysis and dissemination. Other team members were

new to research, and their role on the research team was focused on a very specific component of

the research process, such as serving as SDCDM coaches or revising the PEIS questions. For

these members, their capacity for research was enhanced through a variety of approaches

including formalized training, peer mentorship from more experienced members, and the hands-

on experience of engagement in the process, as has been documented in other studies (García

Iriarte et al., 2014; Garcia-Iriarte et al., 2009; Kramer et al., 2022).

Time and Financial Constraints Impacted Collaboration in all Phases of Implementation

All research requires time and resources to ensure quality and rigor. In the United States,

funding agencies and foundations are increasingly recognizing the value of research partners

with disabilities, and operationalize that value through dedicated funding (O'Brien et al., 2022;

PCORI, 2023). Still, the work of experts with IDD is often significantly undervalued and

undercompensated relative to non-disabled peers (Nicolaidis et al., 2019). The systemic

persistence of institutions undervaluing and undercompensating the labor and expertise of

partners with disabilities presents a significant barrier to inclusive research (Garratt et al., 2022;

O'Brien et al., 2022). Both projects were fortunate to have the financial support and resources

needed to implement inclusive research. While the PEIS workgroup had time and budget in the

beginning to expand the work to ensure meaningful collaboration and high-quality development

process, it meant less time and funds to engage with the team at the end in data analysis and final

decision making. However, the intensive engagement of one member (Peace Urquilla) in this

process ensured the voice of people with lived experience were present in all phases of the

project. For the SDCDM project, there was not time or budget to engage participants in the IRB

process, which limited their engagement in data collection and analysis. Further, time constraints

prevented robust discussion of the research process, so while facilitators gained extensive

knowledge in the SDCDM and facilitation techniques, facilitators did not always have

information about the context of delivering the SDCDM as part of a research study. Even with

these limitations, both projects' ability to secure resources and fairly compensate partners speaks

to a deeper, values-driven approach that was foundational to the success of our teams.

Conclusion

This manuscript illustrates how two studies implemented research in collaboration with

people with IDD, using consensus inclusive research attributes as a common framework. The

implementation of inclusive research, as aligned with these attributes, is strengthened when

teams build trusting relationships, are adaptable to changes in the team over time, facilitate

ongoing capacity building by inviting people with IDD to collaborate at multiple levels of a

project, and are supported with sufficient financial resources. As illustrated by the outcomes of

the two inclusive projects described in this paper, the PEIS workgroup and the SDCDM over

telehealth, everyone learns from the collaborative process which results in better research and

meaningful products.

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Table 1: Aligning the PEIS Workgroup and SDCDM via Telehealth project with the consensus attributes in Frankena and colleagues (2019)

Attributes of Inclusive Research	Study 1: PEIS Workgroup	Study 2: SDCDM via Telehealth
Facilitating the process		
Discussing team members practical and emotional needs and responding to them as a team	• All members shared their character strengths during the first meeting. • The 9th wrap-up meeting included a strengths – spotting exercise with team members to celebrate their contributions to the team.	• Before the first meeting, and weekly throughout the project, the Facilitator Supporter met individually with each facilitator with lived experience to discuss any supports that were needed for either the coaching sessions or SDCDM sessions. • The all facilitators were encouraged to share any feedback on ways the team could better support their needs.
Developing easy to read info (accessible and continuously tested)	• An easy read agenda and accessible PowerPoints™ were used for each meeting	• A one-page, plain language description of each session with embedded visual supports were created for each SDCDM session • Plain language PowerPoint slides were created for all facilitators to use to teach concepts
Considering prep for meeting (mentoring, pre-meeting)	• The agenda and materials were sent to members prior to each meeting. • Members could schedule a one-on-one prep session.	• Facilitators with lived experience met weekly with the Facilitator Supporter to prepare for SDCDM sessions and bi-weekly with SDCDM coaches to problem solve challenges with participants and SDCDM facilitation
Communication routines- taking turns, not answering for others	• Zoom polls were used in meetings to gather initial feedback on each item to ensure all perspectives were represented. Open discussed was based on poll results.	• Coaching sessions followed a predictable routine, including unstructured "get to know you" time, progress reporting, and problem solving.

	• A member identified the use of the teleconferning "raise hand" function to indicate when others wanted to share so members could self-monitor their contributions.	• One facilitator emerged as the leader of the "get to know you" time and came with questions to ask the group.
Open discussion about structure of team meetings, location, time, socialization, how to manage conflicts	• We identified a common meeting time that worked for all members. • Each meeting opened with a 'question of the week' to build relationships among members. • Members were given the options to discuss content individually if they missed a meeting, but could miss group meetings as needed due to work, health, or personal commitments.	• During synchronous the first SDCDM training session, all facilitators practiced using the teleconferencing software for facilitation. • All facilitators agreed on meeting etiquette, including staying muted until it was their turn to talk and waiting until someone was finished speaking before unmuting.
Using tools to support the learning process (handbooks, videos, training)	• The first meeting included an orientation to PEIS by a team member with lived experience, and a discussion of shared values.	• All facilitators participated in two hours (divided into 30 minute chunks) of asynchronous remote training designed to teach components of the SDCDM • All facilitators participated in two hours of synchronous remote training where the coach modeled a SDCDM session and all facilitators practiced their facilitation.
Ensuring ongoing critical reflection and evaluation and adjusting as required	• The feedback process was adapted to remove a step that felt repetitive based on input from members.	• During coaching sessions and weekly preparation sessions, coach and supporter asked reflective questions about SDCDM session.
Considering equality training for entire research department	• Co-I Kramer and engagement coordinator had a combined 17 years of experience partnering in the design of accessible and relevant products.	• The research team included researchers with IDD and PI Dean and Co-PI Shogren had experience conducting research with researchers with IDD.
Dealing with practicalities		

Discuss transportation needs, and arrange and fund transportation as needed	• This did not apply as the workgroup met on zoom.	• This did not apply as meetings were held on zoom.
Allow for extra time to implement all aspects of an inclusive project	• The workgroup increased the initial timeline from 5 to 9 meetings to ensure sufficient time for feedback.	• We did not plan for this and needed to build in extra time for facilitators to complete the 6-month intervention timeline.
Plan for short and long term breaks	• Meetings were kept at 1 hour and no break was needed. • A wrap up celebration was held during the 9th meeting to reflect on accomplishments. • Members attended an update meeting after the completion of content validity evaluation.	• We kept meetings to one hour – which was the preference of people with IDD on the team – and breaks were not needed. • Throughout the 6-month timeline, all facilitators were encouraged to take vacations and sessions were halted during holidays. • When facilitators with lived experience took vacations, the Facilitator Supporter and coach supported them to identify strategies to catch up with the timeline (e.g. meet with participants twice in one week).
Discuss how team members need to be supported and provide support- example, research staff for research and support staff for accessibility	• All members attended and engaged over Zoom without direct support.	• Held a technology training session where all facilitators learned to connect to sessions, share their screen, and mute/unmute their microphone. All implementation materials were kept on a website for easy access during SDCDM sessions • Some facilitators with lived experience preferred print materials, so booklets of session materials were created.
Discuss with support staff how they can support researchers wth ID	• One member requested to have his family cc:d on all emails.	• Researchers observed recordings of SDCDM sessions and if a training or support need was identified by the research team, we discussed the need with the facilitator and Facilitator Supporter to identify needed supports.
Discuss how to deal with scientific research team	• One member was also a member of the Leadership Team. This member had	• One researcher with IDD attended all research meetings. This researcher was involved with the

meetings which people with ID may find challenging to attend because of technical and complicated forms	experience engaging in scientific research team meetings.	development of the study, including developing procedures for training facilitators with lived experience and co-developing training materials in plain language. • The research team worked to reduce jargon used for research team meetings, provided plain language materials in advance of meetings, and the PI met regularly with the researcher with IDD to talk through the purpose of the meetings and support the researcher to think through their contribution to the meeting.
Generating data		
Discussing and identifying what is needed to collect and process data. Provide training if needed	• Members identified the importance of providing individualized accommodations during PEIS administration for both research participants and mental health clients	• Decisions about identifying and collecting data were made by the research team, including one research team member with IDD
Use alternative means of data gathering (video, visual)	• Members helped design the easy read definition of mental health providers and services, and the PEIS visual response scale that used familiar words, colors, and symbols.	• Data collection occurred through an online system developed by the research team. During coaching sessions, all facilitators were trained in procedures to protect confidentiality.
Identify ways to generate data using creative means	• Not addressed	• As part of SDCDM facilitation, all facilitators were trained to support participants to set SMART goals and develop goal attainment scales based on the SMART goals.
Identify issues of confidentiality and develop solutions	• Members stressed the importance of explaining to both research participants and mental health clients how their PEIS responses would be used	• Opportunities for facilitators with lived experience to collect data were limited by timeline and funding challenges for completing IRB trainings. • All facilitators received training in confidentiality from the SDCDM coach.
Analyzing data		

| Discuss and identify means to analyze data with team | • One member contributed to the coding of qualitative content validity data as part of their other responsibilities on the research team. They completed a 1 month long team training on qualitative data coding, and had previous experience coding qualitative data.
• When encountering responses that were negatively biased about persons with IDD, they found it difficult to engage in the process. They were reassigned to code data that were more neutral. | • Data analysis has not yet occurred, but the research team plans to involve facilitators with lived experience in the interpretation of the analysis using deidentified, aggregated data.
• Through coaching conversations, facilitators with lived experience were instrumental in identifying key discussion points that added context and real-world applicability to the data. |
| Compare and discuss ideas about pattern response with team | | |

Table 2: Roles of the PEIS Workgroup and the broader research project

Role	Description
PEIS workgroup members	Four persons with variety of different experiences of disabilities and all with mental health service experiences. All members also served on the broader project's Advisory Council, and two members had other roles and responsibilities on the study team (Leadership Team, Engagement Team).
PEIS workgroup facilitators	Two persons without disabilities, who facilitated the development and review of the PEIS and partnered with workgroup members to ensure the review process was accessible. One was a project Co-Principal Investigator, and the second was the Engagement Coordinator.
Leadership team	Project Principle Investigators, co-Investigators, and other key personnel including research coordinators, engagement coordinator, and a Researcher with a Disability who also engaged in the PEIS Workgroup.

Table 3: Description of priority PEIS administration directions and supports identified by the PEIS workgroup members

PEIS Administration Priority	Features & Supports
Clearly define mental health providers and services	The PEIS workgroup ensured the accessibility of a one page plain language infographic that describes three types of mental health providers and services: prescribers, therapists/counselors, and crisis response. Each definition includes a visual icon to support understanding. Each definition includes examples of types of providers. For example, a prescriber may be a primary care doctor, nurse, or psychiatrist.
Ensure the respondent understands how their responses will be used	The PEIS Administration manual and instructional video includes statements suggested by the PEIS workgroup members such as: • "My job is to listen to you and do what I can to help your mental health providers improve services if needed. What you tell me today won't be shared with your providers. If you would like me to share with other people, like your family, we can do that together." • "Remember, there are no right or wrong answers! What you think is important."
Provide accommodations to allow all persons to share their perspectives using the PEIS	The PEIS Administration manual and materials are accessible and allow additional accommodations. Access accommodations developed in partnership with the workgroup include: • The PEIS Response scale includes visual cues using colors and symbols • Persons can take breaks as needed, or complete the PEIS over several sessions • A trusted support person, such as a family member, can be present during administration. • PEIS questions can be modified to include references to the person's specific mental health providers and services • PEIS response scale words and images are available as picture exchange cards, or can be programed into communication devices.

Table 4: Roles of SDCDM via telehealth personnel

Role	Description
Coach	Met bi-weekly with facilitators to problem solve challenging implementation situations and enhance fidelity
Facilitator	Met weekly directly with participants to support participant to work through the SDCDM
Facilitator Supporter	Trained SDCDM facilitator who met weekly with facilitators with lived experience to prepare for SDCDM sessions
Participant	Person working through the SDCDM

Table 5: Description of SDCDM via telehealth training and support components

Training and Support Component	Features
SDCDM Session Materials	**Detailed SDCDM Session Descriptions** – described the Person Questions and Facilitator Objectives for the session in plain language. Also provided detailed plain language descriptions of each PPT slide with a sample script for how to introduce content on each slide. **SDCDM Session One Page Overview –** a quick reference asked for and designed by people with lived experience to give an overview of the session purpose and key activities **PPT slides** – designed to support facilitators to teach key SDCDM concepts **SDCDM session activities** - designed to engage participants in meeting session objectives.
Structured Training Process	**Asynchronous Remote Training** – 3 hours of videos teaching the main components of the SDCDM (content was broken into 30 minute segments). **Synchronous Remote Training** - two hours of remote "face to face" training where an expert in SDCDM implementation modeled an SDCDM session, facilitators practiced facilitating an SDCDM session, and facilitators planned for their implementation.
Prep Sessions	Facilitators with lived experience met weekly with another trained SDCDM facilitator to plan that week's SDCDM session
Coaching Sessions	Facilitators meet bi-weekly with an SDCDM coach. Coaching sessions were divided into three components 1) Unstructured "get to know you" time 2) Reporting, where facilitators shared their experiences facilitating the SDCDM 3) Problem Solving, where the SDCDM coach facilitated a conversation to resolve challenges faced by facilitators and enhance facilitator problem solving