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"Presuming competence and assuming that accommodations will be the inroads to access and participation": factors facilitating inclusive research and peer mentoring as opportunities for social inclusion for people with intellectual/developmental disabilities

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Dissertation

“PRESUMING COMPETENCE AND ASSUMING THAT ACCOMMODATIONS WILL BE THE INROADS TO ACCESS AND PARTICIPATION”: FACTORS FACILITATING INCLUSIVE RESEARCH AND PEER MENTORING AS OPPORTUNITIES FOR SOCIAL INCLUSION FOR PEOPLE WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

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DEDICATION

To my grandfather, Andy Miklos, who was always curious and driven by his values.

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“PRESUMING COMPETENCE AND ASSUMING THAT ACCOMMODATIONS WILL BE THE INROADS TO ACCESS AND PARTICIPATION”: FACTORS FACILITATING INCLUSIVE RESEARCH AND PEER MENTORING AS OPPORTUNITIES FOR SOCIAL INCLUSION FOR PEOPLE WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

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ABSTRACT

People with intellectual/developmental disabilities experience exclusion from social spaces. In this dissertation, I address social inclusion in: a) research and b) peer relationships in the context of mental health services.

To address inclusion in research, we conducted key informant interviews with academic researchers (n = 8) and co-researchers with intellectual disability (n = 6) who have expertise in inclusive research (study 1). Using principles of grounded theory we analyzed the data and developed a conceptual model describing the contextual factors and team-level factors that coalesce to foster and maintain inclusive research collaborations. We found that team members’ values and characteristics influence inclusive research collaborations and drive a commitment to accessibility. Additionally, perceived personal and societal benefits contribute to co-researcher involvement. Contextual factors, including funding and partnership duration, influence teams’ processes and structures. These processes and structures influence the extent to which co-researchers perceive the

inclusive research team to be co-facilitated or academic-facilitated. This model describes how contextual and team-level factors and processes may be optimized to support co-researcher engagement in inclusive research.

To address peer relationships in the context of mental health services, I used a stakeholder-driven approach to develop a peer mentoring intervention for young adults with intellectual/developmental disabilities and co-occurring mental health conditions (study 2). This approach included partnership with 3 young adults with intellectual/developmental disabilities and co-occurring mental health conditions and a 7 member advisory board composed of self-advocates and professionals. In addition, I conducted focus groups with mental health clinicians ($n = 10$), peer support specialists ($n = 9$), and transition specialists ($n = 20$) to identify the desired peer mentoring outcome and intervention components and content that may facilitate these outcomes. The focus group participants identified several relationship-driven and outcome-driven actions peer mentors may use to support outcome achievement. Stakeholders also identified five components relevant to the intervention: safety considerations, mentor matching, degree of intervention structure, mentor training and support, and collaboration with mentees' support teams. These findings draw attention to the importance of social relationships and individualization of both mentoring and supports for mentors.

Together, these two studies highlight the importance of valuing the unique strengths of people with disabilities and the need for task and environmental adaptations to foster social inclusion of people with intellectual/developmental disabilities.

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LIST OF ABBREVIATIONS

IDD-MH: Intellectual/developmental disability and co-occurring mental health condition

IR: Inclusive research

MHC: Mental health clinician

PP: Peer provider

TS: Transition specialist

DEFINITIONS

Academic researcher:[1] A research team member who does not have an intellectual/developmental disability and has completed academic research training

Co-researcher:[1] A research team member with an intellectual/developmental disability and without academic research training

Developmental disability: Cognitive and/or physical impairment with onset before age 22 resulting in functional limitations in at least three of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency (Developmental Disabilities Act, 2000).

Inclusive research: Research that involves collaboration with individuals with intellectual/developmental disabilities in the research process.

Intellectual disability: "A disability characterized by significant limitations in both intellectual functioning and adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (American Association on Intellectual and Developmental Disabilities).

Peer provider: A provider "who uses his or her lived experience of recovery from mental illness and/or addiction, plus skills learned in formal training, to deliver services in behavioral health settings to promote mind-body recovery and resiliency" (Substance Abuse and Mental Health Services Administration).

Transition specialist: A school-based professional who works with special education students ages 14–22; this may include special education teachers, social workers, certified transition specialists, occupational therapists, employment specialists, etc.

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[1] It may be possible for individuals to have overlapping identities as a co-researcher and an academic researcher, as some people with disabilities acquire academic training through higher education programs.

INTRODUCTION

People with intellectual and developmental disabilities experience significant health and wellness disparities. This group is more likely to develop chronic diseases, lack access to healthcare, be unemployed, have limited community and social participation, and decreased quality of life (Anderson et al., 2013; Biggs & Carter, 2016; Butterworth & Migliore, 2015; Krahn & Fox, 2014; Simões & Santos, 2016; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Disability rights advocates assert that these disparities are a result of societal oppression, rather than innate differences. This oppression is driven by social, economic, and political institutions (Oliver, 1990). One effect of these oppressive institutions is social exclusion, in which people with disabilities do not have equal access to opportunities. Social exclusion spans the life course and contexts. It can take the form of exclusion from education, work, community living, social and material resources, and relationships of all types—peer, familial, intimate, etc. (Charlton, 1998; Oliver, 1990). In this dissertation, I discuss two types of social exclusion and offer potential steps to counter systematic oppression of people with intellectual disability with regard to a) inclusion in research and b) peer relationships.

Inclusion in research

Similar to other marginalized and subordinated groups, academic research has a dark history of exploiting people with intellectual and developmental disabilities for their benefit. For example, in the 1950s, people with intellectual disability living in institutions were subjected to polio vaccine trials and inoculation with hepatitis without their consent (Smith & Mitchell, 2001). In response to these injustices, ethical standards have been adopted to ensure that people from marginalized groups are not harmed and have opportunities to benefit from research in which they participate (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Often these guidelines have prevented people with intellectual and developmental disabilities from participating in research, despite their interest in being involved in knowledge production as participants and researchers (McDonald et al., 2016; McDonald, Conroy, Olick, & Project ETHICS Expert Panel, 2018). Disability rights activists have argued that protections that prescribe guidelines for participation *as research subjects* fall short. Echoing the rallying cry of the disability rights movement, "nothing about us without us," they have argued that academic institutions will continue to exploit people with disabilities until academic researchers partner with them. Furthermore, disability rights activists have argued that their involvement in research is critical to produce knowledge that is relevant to and benefits their lives (Kitchin, 2000; McDonald & Raymaker, 2013; Zarb, 1992).

In turn, advocates, funders, and agencies, such as the Patient-Centered Outcomes Research Initiative (PCORI), have recognized that one potential cause of observed disparities experienced by people with intellectual and developmental disabilities is that health and rehabilitation research has failed to consider the needs, interests, and lived experiences of this group (Frank, Basch, & Selby, 2014; Frankena, Naaldenberg, Cardol, Linehan, & van Schrojenstein Lantman-de Valk, 2015). When people with intellectual and developmental disabilities are excluded from the research process, academic researchers without disabilities may overlook underlying causes of disparities and potential solutions to resolve them. Conversely, when people with intellectual and developmental disabilities are involved in conducting research, they can draw upon their lived experiences to identify the root causes of problems, propose optimal solutions, identify relevant research questions about those solutions, develop appropriate data collection methods, increase access to the community via their active involvement in data collection, and provide valuable perspectives during data analysis and interpretation (Bailey, Boddy, Briscoe, & Morris, 2015; Nicolaidis et al., 2011; Nind & Vinha, 2014).

Since the 1990s, there has been an increased effort to include people with intellectual/developmental disabilities as research partners (Stack & McDonald, 2014; Walmsley & Johnson, 2003; Walmsley, Strnadová, & Johnson, 2018). Researchers from diverse fields have partnered with people with disabilities to address the expressed concerns of people with disabilities using an array of approaches. “Inclusive research” is an umbrella term used to describe, “research in which people with [intellectual disability] are involved as more than just research subjects or respondents” (Walmsley, 2001, p. 188). This term encompasses research in which people with disabilities have a range of roles and control over the research, including emancipatory research, participatory action research, community-based participatory research, and stakeholder/patient-engaged research (Frankena et al., 2015). Despite the increase in inclusive research, people with disabilities and academic researchers have not identified how to optimize collaboration in inclusive research. The first study of this dissertation builds on previous research describing inclusive research and proposes a model for inclusive research collaborations with people with intellectual disability. Specifically, the first study describes qualitative research that sought to understand the processes that foster and maintain collaboration and involvement of individuals with intellectual disability in inclusive research. The second study of this dissertation describes one stage of an inclusive research project, thus contributing an additional example of inclusive research in practice.

Peer relationships

Social inclusion for people with disabilities takes diverse forms. Since deinstitutionalization, great gains have been made in the visibility of people with disabilities in the community and opportunities for inclusion in community life (Wehmeyer, 2013). Social inclusion not only involves inclusion amongst people without disabilities, it also refers to relationships between people with disabilities. Disability studies scholars suggest that when people with disabilities are isolated from each other, their status as "inferior" citizens is reinforced, and they do not have opportunities to develop a collective empowered disability identity (Charlton, 1998). This is further reified when we assume the goal of "community participation" is to engage in "non-disability" settings, in which individuals may be the only person with a disability present.

While educational practices (e.g., segregated classrooms) and policies (e.g., enrollment in specialized programs until age 22) provide school-aged individuals with intellectual and developmental disabilities many opportunities to develop relationships with each other, after graduation from high school, this population often experiences isolation from both the disability community and people without disabilities. This social isolation is due to the increasing trend of young adults living with their families rather than in congregate settings (Bershadsky et al., 2012; Hall, 2005; Young-Southward, Cooper, & Philo, 2017). Social isolation is even greater for individuals experiencing mental health symptoms and challenges and may exacerbate these challenges (Stalker, Jahoda, Wilson, & Cairney, 2011). The absence of positive peer relationships reduces the likelihood of developing and maintaining an empowered disability identity (Caldwell, 2011; Charlton, 1998), which may further contribute to mental health symptoms and challenges during this transitional life stage in which young adults are actively engaged in identity formation (Arnett, 2000).

Recognizing the importance of peer relationships for wellness, the mental health recovery movement draws heavily upon peer support to promote positive outcomes. Peer provided services have long been considered best practice and a crucial component of community-based mental health services for individuals with mental illness without intellectual/developmental disabilities (Jacobson & Curtis, 2000; Vanderplasschen, Rapp, Pearce, Vandevelde, & Broekaert, 2013). In this model, peers with mental health conditions partner with individuals experiencing acute and chronic mental health symptoms to achieve individualized goals and overall wellness (SAMHSA-HRSA, 2015). This peer-led, community-based model was developed in response to a long history of people with mental health conditions being excluded from decisions about their own mental health care—an experience shared with people with intellectual/developmental disabilities.

Transition age youth with intellectual/developmental disabilities and co-occurring mental health conditions may likely benefit from support that centers on social inclusion, such as peer mentoring. A peer mentoring model may reduce social isolation and exclusion by fostering positive peer relationships (Dennis, 2003; Gidugu et al., 2015; Kohut et al., 2016). The second study of this dissertation describes one stage of an inclusive research project developing and evaluating the feasibility of a peer mentoring intervention for transition age youth with intellectual/developmental disabilities and co-occurring mental health conditions. Specifically, we describe a multifaceted stakeholder-driven approach to selecting the format and desired outcome of the peer mentoring intervention. We also identified features and content considerations for an effective and feasible peer mentoring intervention for young adults with intellectual/developmental disabilities and co-occurring mental health conditions. Because efforts of "social inclusion" are often focused on integration with non-disabled communities, it is the hope that this model of social inclusion highlights the strengths and unique value of peer relationships between young people with shared disability identities.

Study 1

“That felt like real engagement”: Fostering and maintaining inclusive research collaborations with individuals with intellectual disability

Abstract

People with intellectual disability are increasingly involved in stakeholder-engaged research, such as “inclusive research” (IR). To understand the processes that foster and maintain IR with individuals with intellectual disability, we used a narrative interview approach with co-researchers with intellectual disability (*n*=6) and academic researchers (*n*=8). We analyzed the data using grounded theory principles. We then developed a model describing how contextual factors and team-level factors and processes coalesce to foster and maintain IR collaborations. We observed that team members’ values and characteristics are foundational to IR and drive a commitment to accessibility. Contextual factors, including funding and partnership duration, influence teams’ processes and structures. These processes and structures influence the extent to which co-researchers perceive the IR team to be co-facilitated or academic-facilitated. Co-researcher involvement is partially maintained by perceived personal and societal benefits. Optimizing the relationship between these factors may support involvement of people with ID in stakeholder-engaged research projects.

Introduction

Researchers in health-related fields have long recognized the value of including stakeholders from marginalized groups in the research process to address power imbalances, improve quality of life, and reduce health disparities (Kidd, Davidson, Frederick, & Kral, 2018). Accordingly, researchers concerned with the wellbeing of people with intellectual disability are increasingly turning to stakeholder-partnerships to address disparities this group experiences in areas such as access to healthcare (Anderson et al., 2013; Krahn & Fox, 2014; Vazquez, Khanlou, Davidson, & Aidarus, 2018), employment (Butterworth & Migliore, 2015), community and social participation (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009), and quality of life (Biggs & Carter, 2016; Simões & Santos, 2016).

Inclusive research (IR) is a broad term used to refer to any “research in which people with [intellectual disability] are involved as more than just research subjects or respondents” (Walmsley, 2001, p. 188). “Inclusive research” is increasingly used as an umbrella term to refer to research collaborations with people with intellectual disability[2], including approaches such as participatory action research (PAR), community-based participatory research (CBPR), patient-engagement research, and emancipatory research. Like other approaches, IR has its roots in systems change and Freire’s critical pedagogy (Walmsley & Johnson, 2003). Walmsley and Johnson (2003) described five principles of IR that are aligned with CBPR principles (Israel et al., 2008), while also reflecting

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[2] This term has also been used to describe research with other disability populations, including people with developmental disabilities (e.g., autism) who do not have intellectual disability.

considerations unique to people with intellectual disability, such as the specific ways in which they experience marginalization and their support needs. These principles are: 1) “The research problem must be one that is owned (not necessarily initiated) by disabled people”; 2) “It should further the interests of disabled people; non-disabled researchers should be on the side of people with [intellectual disability]”; 3) “It should be collaborative-people with [intellectual disability] should be involved in the process of doing the research”; 4) “People with [intellectual disability] should be able to exert some control over process and outcomes”; and 5) “The research question, process and reports must be accessible to people with [intellectual disability]” (Walmsley & Johnson, 2003, p. 64).

Determining how to operationalize these principles is essential to fostering and maintaining IR collaborations. To date, the literature on IR has primarily included descriptive and post-hoc accounts of a single research study (e.g., O’Brien, McConkey, & García-Iriarte, 2014; White & Morgan, 2012). These accounts shed light on how to support access to the research process for people with intellectual disability and critically reflect on power sharing within each study. Adding to this, literature reviews (Bailey, Boddy, Briscoe, & Morris, 2015; Frankena, Naaldenberg, Cardol, Linehan, & van Schrojenstein Lantman-de Valk, 2015) and consensus statements (Frankena et al., 2019; Telford, Boote, & Cooper, 2004) have listed strategies and attempted to describe how to use these strategies to operationalize IR principles across a range of contexts. While informative, IR teams are inherently dynamic social systems, and we still do not know whether these strategies transfer across different contexts (Nind, 2017) or how strategies relate to each other and contextual factors.

Nind and Vinha (2014) recently conducted focus groups in Europe with inclusive researchers with and without intellectual disability and proposed a model to describe how research teams with diverse structures work together. Whereas previous reviews have focused on static measures of collaboration such as specific ways in which co-researchers with intellectual disability contributed to the research (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014; Stack & McDonald, 2014), Nind and Vinha's model acknowledged the dynamic and situated nature of collaborations. Their model describes how teams may have "formalized" and "improvised" ways of working together and that support, negotiation, and interdependence may be emphasized differently across teams. However, this broad and descriptive model leaves the field still lacking a conceptual model that describes how contextual factors and team-level factors and processes coalesce to foster and maintain IR collaborations with individuals with intellectual disability. Such a model could help researchers identify when and how to implement strategies and hypothesize the relationship(s) between these strategies. Understanding these relationships may inform future empirical studies of IR process and support researchers to collaborate with people with intellectual disability in diverse projects.

To understand how these factors foster and maintain IR collaborations, we conducted key informant interviews (Marshall, 1996) with experienced inclusive researchers with academic training ("academic researchers") and researchers with intellectual disability ("co-researchers"). Qualitative research is suited to meet this goal, as it is a tool for elucidating complex processes and allows for exploration of conceptus not fully understood and ready for experimental study (Maxwell, 2013). Additionally, a qualitative approach directly includes the perspectives of co-researchers with intellectual disability—voices which have been excluded in most conceptual discussions of IR (Di Lorito, Bosco, Birt, & Hassiotis, 2018).

Methods

All methods, including accessible consent approaches, were approved by a university IRB. Although we did not use an IR approach, we developed our research question based on a review of the literature and our own experiences with IR (e.g., Kramer & Schwartz, 2018; Kramer & Schwartz, 2017). The first author worked directly with a paid co-researcher with intellectual disability to refine the interview protocol and co-conduct interviews with co-researchers. This research assistant was an experienced researcher with whom some of us (AS, JK) had worked for five years, and this work benefited from his expertise.

Recruitment and sampling

To identify key informants, we recruited academic researchers (including student researchers) in English-speaking countries. Inclusion criteria for academic researchers was: a) Experience with at least two IR studies with people with intellectual disability or experience with a single IR study for ≥4 years, b) at least one IR study published in a peer reviewed journal, c) ability to communicate using English, and d) at least one IR experience in the last 12 months (to foster accurate and detailed recollection). Academic researchers then referred potential co-researchers from their projects and sought permission for us to contact them directly. Inclusion criteria for co-researchers was: a)

Diagnosis of intellectual disability, b) ability to communicate using English, and c) at least one IR experience in past 12 months. Because the population meeting these criteria is small, to balance our recruitment needs with diversity of experiences, we included individuals who had shared experiences on the same IR project, provided at least one of the key informants had experience with a separate IR project.

Participants

We interviewed academic researchers (*n*=5) and co-researchers (*n*=5). After we developed a preliminary model, we interviewed additional academic researchers (*n*=3) and one co-researcher to triangulate the model. We were unsuccessful in recruiting additional co-researchers for this stage. Table 1 includes details about the participants' backgrounds (total n=14) and experiences with IR; we limit demographic details to protect participant confidentiality.

Researcher positionality

The first author (AS), an occupational therapist with a background in disability studies, had at the time, five years of experience conducting IR with young adults with intellectual and developmental disabilities. From her experiences, she believed that the IR setting is inherently a social context imbued with power differentials and that individuals with intellectual disability have the potential to access IR when the process is made accessible. The first author led all research processes with the guidance of the other authors, who were members of her dissertation committee: at the time, the second author (JK) had >10 years of experience with IR and a background in disability studies, the fourth author (KM) is a community psychologist with >10 years of IR experience and has previously studied IR. Both the second and third (EC) authors are occupational therapy researchers and all authors have expertise in qualitative research.

Interview procedures

We conducted interviews via telephone or internet (e.g., Skype, Google Hangouts) and video and/or audio recorded all interviews. During interviews, we asked participants to share stories about their experiences with IR (see below and table A1 for additional details). Story telling is an accessible method that supports interviewees to provide rich details about their experiences (Arthur, Mitchell, Lewis, & McNaughton Nicholls, 2014). We checked for understanding by reflecting back our understanding of the main idea conveyed in each story. After all interviews, the first author completed field notes documenting reflections, assumptions, and preliminary interpretations about how to foster and maintain IR collaborations (Arthur et al., 2014).

We asked academic researchers to tell stories about IR to elicit their evolving theories and beliefs about how to foster IR collaborations with co-researchers. For co-researchers, to ensure the interview was accessible, we elicited stories about when research was fun, boring or frustrating, important, and not important. We assumed these stories would reveal the spectrum of involvement and collaboration that may be experienced within a research study and the contexts within which these experiences were embedded. We also provided co-researchers with an interview guide written in plain language prior to the interview (Mactavish, Mahon, & Lutfiyya, 2000) and co-conducted the interviews with a researcher with intellectual disability. The involvement of a researcher with intellectual disability may have increased co-researchers' comfort, leading to a greater depth of discussion than if the interview were conducted only by a researcher without a disability (Mirra, Garcia, & Morrell, 2016). We also invited co-researchers to include a support person (e.g., friend, paid supporter) of their choice (McDonald, 2012); only one co-researcher chose to include a support person. Finally, we "set the stage" at the beginning of the interview by asking factual questions to help participants recall details of their work to facilitate comfort and reflection (Arthur et al., 2014).

Analysis

We created de-identified and verbatim transcripts and analyzed the data using principles from grounded theory, as we sought to build a conceptual framework emergent from the data (Charmaz, 2014). Throughout analysis, the primary coder (AS) consulted with the second author on a weekly basis. The second author also listened to all interviews. In addition, the primary coder created an audit trail by documenting the interview and analysis processes and memoing to record assumptions, questions, and intermediate conclusions (Maxwell, 2013).

Working with one transcript at a time, the primary coder read each transcript without coding it to become familiar with the data. Next she marked passages that reflected processes (specific, systematic, and consistently used procedures) and contextual and team-level factors related to collaboration and named these passages with open codes that "[stuck] closely to the data" (Charmaz, 2014, p. 112). The primary coder then organized open codes into categories of similar meaning to define initial codes. Using NVivo data analysis software, she recoded the data using the initial codes. After reviewing all data captured by each initial code, the primary coder organized initial codes into superordinate units of meaning, defined focused codes, and applied the focused codes to the data. A trained graduate research assistant who had not been involved in the development of the codes triangulated this stage of analysis by applying focused codes to four transcripts. Then, to ensure the focused codes adequately captured relevant processes and factors, we examined how often focused codes were used across participants and discussed challenges differentiating between codes to refine, remove, and expand the focused codes. Next, the first author explored relationships among focused codes by using NVivo matrix coding and developing concept maps (Bazeley, 2013) and narrative summaries for each participant (Spencer, Basualdo-Delmonico, Walsh, & Drew, 2014). Finally, we examined relationships between frequently occurring focused codes within and across participants. We collapsed related focus codes into themes and developed a conceptual model describing how contextual factors and team-level factors and processes coalesce to foster and maintain IR collaborations.

To evaluate whether the model adequately described the data, the first author constructed tables with data that represented each theme in the conceptual model for each participant. The second author triangulated the analysis (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014) by using the same table structure to analyze the data for four participants. At this stage, we searched the data for important concepts that were not represented in the conceptual model.

Triangulation interviews. We conducted four additional interviews (three academic researchers and one co-researcher; see Table 1) to examine the transferability of the preliminary model to additional research contexts. These interviews followed the same protocol as described above, with the addition of interview questions to clarify constructs in the proposed model. The primary coder applied focused codes to these interviews and constructed matrices to evaluate the fit of the preliminary model to the data. These interviews did not lead to any changes in the model, which suggests salience of the model across a range of IR contexts.

Member reflections. To enhance the transferability and confirmability (Letts et al., 2007) of the model and "generate additional data and insight" (Smith & McGannon, 2018, p. 108), we conducted member reflection interviews with two academic researchers and two co-researchers. Prior to the interview, we sent participants a video narrated in plain language describing each theme in the conceptual model. Co-researchers were provided with a customized video that included quotes from their interviews that represented each theme in the model, in addition to a worksheet asking for feedback on each component of the model. We asked participants to provide feedback on the model's applicability to their experience. Their feedback led to changes in how we described the influence of contextual factors.

Findings

We identified six themes that informed our model describing IR collaborations. We first present each of them separately, and then together within the proposed conceptual model (figure 1).

“We are a significant part of this”: The characteristics of team members influences IR collaborations

All participants described how the values and characteristics (e.g., skills, experiences, interests, and motivations) of research team members influenced their work together. Academics and co-researchers shared similar values that underpinned their research teams’ approaches. All academics and most co-researchers stated their value for inclusion, as articulated by the disability rights movement’s motto, “nothing about us without us,” and cited this value as a driver of their research team’s approach and for co-researchers, a strong motivator to engage in research. Participants also spoke about valuing equality, or that “nobody is above anybody else” (C6)[3] and “it’s not hierarchical” (A8). Many academic researchers noted that they subscribe to a social model approach of disability (see Oliver, 1990) and that this approach informs their work.

Academic researchers acknowledged the importance of purposefully and thoughtfully identifying co-researchers. One academic said, “I don’t think we always talk about selection, and I don’t think that being a co-researcher, just as being an academic researcher, is a position for everybody” (A1). This sentiment was echoed by others who spoke of the need for co-researchers, “to be interested in the research you’re doing. They need to be curious and inquisitive” (A5). All participants described the importance of lived experiences relevant to the research topic or other experiences, such as self-advocacy or being peer educators, in which co-researchers are, “already used to speaking

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[3] Quotes are attributed to participants using the notation “C ID#” for co-researchers and “A ID#” for academic researchers.

in public…working on projects” (A2). For example, many co-researchers shared how their experiences with advocacy supported their abilities to connect with others and to complete research tasks: “before I worked [research team], I was a full time volunteer for [city] People First…I guess that skill transferred over” (C6). Co-researchers felt these prior experiences may be why academics invited them to join their research teams: “she kind of thought that, as a self-advocate I would give good things to the research, and to the project” (C1).

Two academic researchers also described the importance of support personnel (e.g., research assistants and personal assistants) having specific skills. It seems that supporters need to have both technical and interpersonal skills to successfully support co-researchers:

> Typically when we’re hiring [research assistants] it’s because of their technical expertise. But…there’s a lot of interpersonal skills that need to come into play. To be able to respect diversity, to be able to develop relationships. (A1)
>
> Just to have a personal assistant doing a lot of the practical day-to-day support—that wasn’t sufficient for her engagement…she also needed that intellectual support, and I felt that it did need somebody who had a background in research. (A7)

Therefore, research teams benefit when there is an optimal combination of skills, motivations, interests, and experiences of all research team members.

“Be dynamic and figure out what’s working and what’s not working”: Making IR Accessible

Researchers’ values regarding inclusion drove academics’ commitment to accessibility. In addition, co-researchers’ values led them to expect the research process to be accessible. As a result, all teams operationalized their values by creating an accessible research environment. Participants described multiple forms of accessibility: “there’s the making the information accessible, and then there’s the making the [research] meetings accessible” (A6). Making all research activities accessible can be time consuming and is often an individualized process. One academic researcher shared that sometimes there are challenges to, “having time to put [materials] in accessible language” (A2). Another challenge is that individuals’ support needs, “at the beginning of a project may be different than at the end,” (A1) which leads to the need for research teams to continually reevaluate accommodations and team processes.

Participants also described strategies documented elsewhere to support accessibility (e.g., Frankena et al., 2019). To facilitate access, all teams attended to the pace of conversation (e.g., “We slowed things down” (A3)) and supported understanding by using plain language. Teams used additional strategies, such as breaking down complex tasks into multiple steps, reducing the amount of text people needed to read, and using visuals. Several co-researchers attended small or one-on-one meetings to prepare for full team meetings. Another way teams increased access was supporting co-researchers to participate and complete research tasks in individualized ways that drew upon their strengths and interests. Many participants described ensuring access by creating a space in which co-researchers felt comfortable to ask questions as needed. One co-researcher shared that it was helpful when, "after [academic researchers are] done explaining things, [academic researchers] say 'does anybody have any questions?'" (C2).

Some academic researchers alluded to debates in the IR community about whether or not co-researchers should be trained in traditional research methods (e.g., conducting interviews, specific types of analysis, etc.) (Janes, 2016; Milner & Frawley, 2018; Walmsley & Johnson, 2003; Zarb, 1992). While several academic researchers suggested that accessible and authentic collaborations are fostered when the research process draws upon individuals' existing skills, one academic more directly asserted, "I think that's not authentic when you have to do things like train people to be researchers…authenticity can only come where we are really playing out that individually responsive approach" (A8). The idea that research training may not be critical for IR collaborations was supported by our observation that most co-researchers had difficulty identifying specific skills they had learned as researchers. Additionally, several co-researchers believed they already knew how to complete research tasks based on prior experiences. For example, one co-researcher shared, "At People First…I was helping out with the men's group, so I know…how to work with focus groups" (C5).

"It is very important to me. I learned a lot of new things": IR collaborations are maintained by perceived benefits

All co-researchers described multiple personal and societal benefits to involvement in IR. Personal benefits included: learning information about interesting topics, developing relationships, finding the research interesting and enjoyable, increased confidence, experiencing success, and being part of a team. For example, they shared, “It was fun when...I got to know more about myself” (C2); “It is very important to me. I have learned a lot of new things” (C3); “All the topics that we talked about were very interested and I learned a lot” (C1); “I think it was just fun meeting everybody and working as a team and just being part of it” (C4); “I felt achievement and using your skills” (C5); “The information [interviewees] give is really interesting” (C6).

All but one co-researcher emphasized that their research projects had societal benefits, primarily positive outcomes for people with disabilities. For example, one co-researcher studying self-advocacy stated, “I choosed it to be my job as a researcher because its…how can the next generation of people who want to set up a self-advocacy group...and then how to better that and how to make it run and keep going” (C5). Another researcher added, “I want to do research, because I like being part of something that might help other people. In a way that's not gonna be harmful” (C4). These perceived benefits may be why many researchers decided to maintain involvement for multi-year projects and/or multiple studies.

Academic researchers also perceived societal benefits as critical to their work. They described projects grounded in the expressed needs of people with disabilities and a commitment to generating outcomes that were meaningful to co-researchers, such as toolkits and plain language reports. While academic researchers may benefit less from these outputs than traditional academic outputs (e.g., journal articles), they felt, “those of us who’ve got the money, time, and resources…may not always have the same objectives, but as long as someone can stand by people with an intellectual disability and mediate their voices into what they want as outcomes" (A8). Thus, supporting co-researchers to realize their desired outcomes can maintain engagement and was also be seen as an ethical imperative.

"There was trust, there was familiarity": The role of relationships

Many participants discussed the importance of relationships for their collaborations. The main concepts related to relationships were familiarity, trust, and how IR provided an opportunity to develop new relationships. Both co-researchers and academic researchers reported that it was helpful for team members to be familiar with each other and that increased familiarity with each other over time could facilitate teamwork. One academic researcher shared, "What happened over time is that, [team members] got a little better at predicting what each other wanted" (A6). In many cases, co-researchers and academics had prior relationships. Still, they had to, "take a bit of time to get to know a person and then once you get to know that person they should know how to understand how that person works and how do yourself work so that you can...co-work together at the same level" (C5). These relationships may support conversations about difficult topics, as one academic researcher shared, "there's just a camaraderie that I think goes a huge way" (A3). When team members didn't have existing relationships dedicating time to, "[get] to know each other was really important" (A4). Teams established relationships by spending time together while traveling for research or eating meals together.

Academic researchers emphasized the importance of trust. They fostered trust by being responsive to co-researchers' input and requests for changes. One academic shared, "there was trust, there was familiarity, the thought that people could be honest and they knew, I think this is a big one, they knew that their feedback would be considered, taken seriously and probably change the course of the work that we did" (A1). Another way academics fostered trust was open and transparent communication by discussing challenges and constraints posed by funders and timelines. One academic researcher described how she grew throughout the time she worked with two co-researchers stating, "In earlier studies, I had the tendency to try to figure it out by myself. If I just involved them in my own struggles, they felt like there were part of the research, even though…they couldn't be part of all the steps we were taking" (A4).

Co-researchers discussed relationships as both a benefit to doing the research and a challenge. When asked about positive aspects of research, co-researchers often said they were able to "meet new people" (C4, C3) and develop relationships with other team members, and sometimes research participants. Two co-researchers also discussed challenging interpersonal situations when within the research team, "people...might not [think] the same way that you think" (C1). However, both said that increased familiarity with team members over time helped them learn about each other's perspectives and resolve these challenges: "you butt heads a little bit…[but]…you become friends" (C4).

Teams' processes and structures facilitate IR collaborations

One way in which teams operationalize their values is through their structure(s) (i.e., how they are organized) and their processes (i.e., how the team works together). Research teams were usually prospectively structured to foster equality and be responsive to co-researchers' input. As needed over time, teams refined their processes for collaborating to maintain co-researcher collaboration.

One important structural component of research teams was the division of labor between academic researchers and co-researchers across phases of research. Some academic researchers described an approach in which, "at each juncture of that work, whether it's program development, evaluation…everything [emphasis] is done collaboratively" (A8). Other research teams did not include co-researchers in all tasks and decision making, depending on resources, other constraints, and the team's beliefs about the purpose of the co-researcher involvement. In general, co-researchers were most often not included in administrative decisions and tasks (e.g., communicating with funders and the IRB, budgeting, etc.). One academic researcher shared:

> But sometimes if it was IRB related or budget related, we didn't really want to waste the community advisors time on the background stuff. And we told them, "we're doing work on the project, but that's just kinda to keep the thing going, not really about what the survey's gonna be or how we're gonna engage in the community." There's just so much to do on a project and we kinda signed up for what community members are responsible for, what academics were responsible for, and what stuff we're gonna meet in the middle. We each knew our parts and were fine with *not* collaborating on some things (A3).

Another academic researcher emphasized the importance of their team structures eliciting co-researchers' conceptual rather than "hands on" contributions: "In most cases, the decision making was made as a group, but the actual implementing it was often done by research assistants…we basically felt that what we needed from them was their…intellectual contributions" (A6). Both of these researchers demonstrate how their teams were structured in a way that emphasized co-researchers' conceptual input. When time or resources limited the ability of teams to include all co-researchers in all decisions, some research teams incorporated the voices of co-researchers in leadership positions. These leaders had responsibilities such as planning meeting agendas or providing input when decisions needed to be made quickly.

Another important structural component was the composition of the research team, including the relative number of members with and without disabilities or specific professional/ educational backgrounds. Two academic researchers described how they tried to, "shift power with numbers" (A1) by including more co-researchers than people without disabilities on their teams. Doing so may increase the voice of co-researchers during voting and group discussion. One co-researcher's comment suggests that the presence of other co-researchers helped her feel more comfortable speaking up:

> I think that someone might have similar experiences, people could actually understand you, versus someone just saying, "I understand," and they really don't. So, I think that's good, because you hear other people, "oh yeah, I can relate,"...but I think that's what's really good about doing this with people that might have the same…experiences. (C4)

Research teams described a range of processes for working together that supported equality and responsivity to co-researchers' input. One way that academic researchers tried to support co-researchers' collaboration was to utilize formal processes to elicit co-researchers' feedback. This often included voting to make decisions. Another strategy used by several teams was "check-ins" at the beginning and/or end of each meeting during which each team member had an opportunity to offer input on the research process.

While academic researchers described how processes for transparency fostered trust, co-researchers described transparency as a factor that factor helped foster equitable collaboration and involvement. One co-researcher shared that he felt he had equal input, because, "when we're doing stuff all the people that are in the building at the time…we always share information" (C6). Another co-researcher described being frustrated when she felt, "out of the loop"; she eventually left this project. When describing her frustrations she said, "Keep us informed. Cause it's hard, because we can't be there every minute. But, I think get everybody's opinion…Keep us more informed" (C4). These quotes demonstrate how intentional and transparent communication is a process that can maintain co-researcher collaboration and involvement.

Teams' structures and the way processes are enacted and perceived influence the extent to which co-researchers share control with academic researchers. Some co-researchers very explicitly described a process of academics seeking their input and the research team acting on (i.e., being responsive to) their input. While these co-researchers *were* authentically collaborating and involved in the research, this process of seeking and acting on input is led by academics. We call these types of collaborations "academic-facilitated." In contrast, other co-researchers spoke less explicitly about academic-driven requests for and responsivity to input. Rather, they described their team's accessible structures and processes as contributing to an IR environment in which co-researchers felt they were equal to academic researchers. For example, some participants described how co-researchers and academic researchers have equal say in what their team does and who performs specific research tasks (e.g., “We’re all given equal job loads. We’re all given equal opportunities” (C6); “We voted…focus groups, which were against my advice were selected” (A2)). We call this type of collaboration “co-facilitated.” Similar to Nind and Vinha’s findings (2014), our sample did not necessarily feel that they were *less* involved in academic-facilitated partnerships, rather, they simply describe team members as having different roles.

“They’re not the sort of people who’ve been hovered in by the trust[4]”: The Impact of Contextual Factors

Contextual factors had a significant influence on teams’ structures and processes, and thus, the type of collaboration. Participants described many contextual factors that influenced the extent to which teams functioned as co-facilitated or academic-facilitated. The most explicitly described factors were time and funding. Other less explicitly described factors included how the project was initiated, which team member(s) were accountable to funders, institutional systems (e.g., payroll and IRB), and previous experiences working together.

Time and funding were often inextricably linked and impacted the structures and processes used by all research teams. Many participants described IR as time consuming.

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[4] “Hovered” in this context refers to “gathering” or “collecting.” “Trust” in this context refers to a national healthcare organization in the United Kingdom.

One reason may be because establishing access is a dynamic process; one academic researcher stated, “ensuring that you’ve got the funding and the resources and the capacity to allow lots of full staff and lots of trial and error is problematic…the way things are funded often you don’t have the opportunity for trial and error” (A7). Often funding impacted the amount of time teams could work together. Another academic researcher shared: “We would like to come more often, more hours a week, or more days a week. But, the co-researchers I worked with, they get an actual salary…But, there's not enough money to have them working here for more hours a week” (A4).

As described above, another consequence of lack of time and/or funding may be that teams have to make decisions about the parts of research in which to involve co-researchers.

The research teams in this study were primarily initiated in two different ways. One, some were assembled in response to an academic researcher acquiring grant funding for a specific project. Two, others were existing teams that apply for grants together. Academic researchers on teams with both types of origins strove to foster collaboration and shift power to co-researchers. While how the team was initiated was not deterministic of how members collaborated, most co-researchers on teams assembled in response to specific grant funding described academic-facilitated collaborations. In contrast, most co-researchers on existing teams described their teams as co-facilitated. One factor that may have influenced this pattern is which team members were accountable to the research funder. For example, two academic researchers on teams assembled in response to specific grant funding (awarded to the academics) shared that one of their roles was to ensure the work stayed within the scope of the grant, conferring the academic researchers power over the project not afforded to co-researchers. For example:

> Part of what was difficult to navigate was…people bringing up an idea, and saying, "that's important, but it's not what we're doing here and we can't include it"…Yes, those things matter and they're really important, and… your self-advocacy group is working on them…but these things are beyond the scope of what we're able to do here…'cause we have a grant from a federal funder, we've got to do a certain set of things. (A1)

Here, although the topic was of interest to people with disabilities, the academic researcher felt she had to ensure she met the aims of the funded grant. In contrast, a co-researcher on a permanently existing team said that their process for choosing the research topic involved, co-researchers. She shared, "we all sat down and we were thinking about what we'd do next in our project and we all thought about [name of project]" (C3). On this and another permanently existing team, co-researchers and academic researchers described working together to plan projects and collaboratively apply for grants. When they do this, they can collaboratively plan team members' roles, how funding will be used, and the scope of the project.

Academics also sometimes felt accountable to the expectations of their work place, and this may have also influenced how teams were structured and worked together. One academic researcher shared the importance of being, "in a context that understands why we're putting in all this extra work to doing our work and understanding that our timelines are going to look different" (A1). The importance of context was echoed by another academic researcher who stated a strong preference for working with teams in which the funding is not held by academic researchers, accountable to universities:

> I think the most powerful IR is when the grant is held…not by the university, but by…a disabled person's organization. I think…when it's held by university, they have certain outcomes they have to achieve, and they might well be scholarly articles, which are not a particularly suitable vehicle for inclusion. (A5)

Proposed Model of IR Collaborations with Individuals with Intellectual Disability

We propose that IR collaborations with co-researchers can be described by the model in figure 1. In both academic-facilitated and co-facilitated research teams, the teams' values drive their commitment to accessibility and the specific nature of supports. Individuals' characteristics are also foundational to IR collaborations and can influence the types of supports needed for access. In addition to accessibility, increasing familiarity between team members over time can support and maintain IR collaborations. Continually renewed commitment and engagement of co-researchers is driven by perceived personal and societal benefits. Teams' structures and processes can influence how teams collaborate and are responsive to co-researcher input. As teams are responsive to co-researcher input, co-researcher involvement may be further reinforced and strengthened. Often, the unique combination of contextual factors influences (though does not necessarily determine) teams' structures and processes, and in-turn the extent to which the team is academic- or co-facilitated.

Discussion

This study led to the proposal of a conceptual model that describes how different contextual factors and team-level factors and processes coalesce to foster and maintain IR collaborations with individuals with intellectual disability. The present study extends previous research by proposing relationships among previously established components of IR such as trust, changes in relationships over time and across multiple projects, specific strategies to support accessibility, benefits of IR, the importance of co-researchers' motivation and interests and academic researchers' values, and the impact of funder and university expectations and constraints (e.g., Di Lorito et al., 2018; McDonald, Conroy, Orlick, & Project ETHICS Expert Panel, 2018; McDonald & Stack, 2016; Stack & McDonald, 2018, 2014; The Learning Difficulties Research Team, 2006; White & Morgan, 2012). We focus this discussion on describing the observed relationships between some of these components.

We observed that participants who described co-facilitated partnerships were typically members of research teams that work together over across multiple projects, supporting the value of, "[IR] careers rather than [IR] projects" (Kidd et al., 2018, p. 78). Below, we describe how contextual factors, including the duration of partnerships, influence teams' structures and processes. We then use theory to pose explanations for how these components influence co-researchers' perception of their involvement. We conclude by describing how these relationships may be applicable to researchers from diverse health-related fields interested in including people with intellectual disability in their research collaborations.

Two related contextual factors, funding and how the team is initiated, influence how teams collaborated. Many researchers working with diverse populations have discussed the tension of needing funding to establish research partnerships, but wanting to develop grant proposals with their research partners (Gustafson & Brunger, 2014; O'Brien et al., 2014). Teams that work together across multiple projects may more readily access opportunities to develop grant proposals together (e.g., Nicolaidis et al., 2011). For example, in this study, two research teams that exist independent of specific funding described making group decisions about what projects they would work on and when to apply for grants. When grants are collaboratively developed, it is possible that co-researchers may feel a greater sense of ownership over the work and have greater influence on the team's structure and processes, including their own roles. When these decisions are made in collaboration with co-researchers, rather than by academic researchers or as a consequence of contextual factors (e.g., lack of time, funding) (Israel et al., 2008), co-researchers may feel that they are part of a co-facilitated team.

Working together over extended periods of time may also lead to changes in teams' structures and processes. Many teams in this study described changing group processes and structures based on co-researchers' feedback and their dynamic needs. As familiarity increases over time, team members were able to identify their own and others' access needs. Examples of changes included: developing new rules for group discussion to support accessibility and adopting new structures that included small group work to help co-researchers feel more engaged and have greater choice over their role. Our study does not document if and how teams changed their structures and processes *across* projects. However, given that changes regularly occurred within projects, it may be fair to assume that teams also change processes over the course of multiple projects. We draw upon causal agency theory (Shogren et al., 2015) and empowerment theories (Zimmerman & Warschausky, 1998) to offer two potential explanations for how changes in group structures and processes over time may influence co-researchers' perceptions of their collaboration and involvement.

Causal agency theory describes the importance of contextual factors and experience in the development of "causality beliefs." This theory suggests that when individuals see their actions change their environment, they are more likely to perceive themselves as an agent of change (Shogren et al., 2015). It is possible that when teams work together over time and across projects, co-researchers have repeated opportunities to see how their input influences the research. As a result, co-researchers may begin to perceive themselves as causal agents contributing to co-facilitated teams.

Theories describing the development of empowerment provide another possible explanation for how perceptions about academic-facilitated input shift over time. We observed that academic researchers often facilitated or led team processes for the purpose of accessibility. For example, academic researchers described supporting co-researcher input by designing activities to reduce cognitive demands or structuring group discussion to prompt co-researchers' input. In both types of collaborations, teams were responsive to co-researcher input, as evidenced by the incorporation of their input into decisions. Similar to causal agency theory, theories about empowerment describe how when individuals see their behaviors lead to changes in their environment, over time, they are more likely to attribute these changes to their own actions and see themselves as agents of change (Zimmerman & Warschausky, 1998). Empowerment theories also describe how co-researchers may draw upon resources in the environment to enact change. These theories suggest that when academic researchers facilitate co-researchers' input, co-researchers may begin to view this facilitation as a support or a resource that they can actively mobilize to take on and exert control (Pigg, 2002; Zimmerman & Warschausky, 1998), and therefore start to see themselves as co-facilitators.

Although we have posed a theoretically-grounded explanation of changing co-researcher perceptions over long-term partnerships, the proposition that co-researchers may view academic researchers' facilitation as a resource is supported by our data. We observed that many co-researchers emphasized that academic researcher support was essential to their ability to be involved. For example, one co-researcher said that he has power when academic researchers, "mak[e] sure that we have a say in what we are talking about…they come to us or…they talk to us...just saying, 'do you understand?'" (C1). This demonstrates how some co-researchers framed supports as a resource. It is possible that the perception of these supports as a resource strengthens through repeated research experiences.

Our conjecture that co-researchers may frame supports as a resource is important when considering the relationship between accessibility and power in IR. Discussions of IR and other stakeholder-engaged research approaches often center on the extent to which co-researchers have power over the research process , including how the team works together (e.g., makes decisions, completes tasks) (e.g., Bigby, Frawley, & Ramcharan, 2014; Stakch & McDonald, 2014; Woelders, Abma, Visser, & Schipper, 2015). Academic facilitation of IR may inherently decrease the power of co-researchers, because in this type of team, academics may select and implement structures and processes without the input of co-researchers. When academics make decisions, even seemingly small ones about team processes and structures, their values and perspectives implicitly guide and shape the research process. This demonstrates the need for further exploration of the processes of power acquisition and perceived control when academic researchers facilitate access to IR. We begin to discuss this below with regard to knowledge production, but acknowledge that systematic research is needed to explore this tension.

There may be other factors that influence the extent of co-researcher collaboration and involvement, and this is an important area of future research. One important factor may be how research teams' values, including their epistemological beliefs, intersect with access. In this study, all researchers' values drove a commitment to accessibility as an ethical imperative. However, we observed that academic researchers held different beliefs about "to what" they ensured access—cognitive access to traditional research methods (e.g., specific methods) or social access to the knowledge production process. Throughout the literature on IR, CBPR, and other stakeholder-engaged approaches, there are discussions about the implications of increasing accessibility by reducing data (Bigby, Frawley, & Ramcharan, 2014) or, as described by some academic researchers in this study, holding back on theorizing (Walmsley & Johnson, 2003). These discussions point to a critical issue in IR regarding what is meant by "research." Some scholars argue that rather than enhancing access to the traditional tools of academia, IR implores us to think beyond traditional approaches to knowledge production (Janes, 2016; Milner & Frawley, 2018; Walmsley & Johnson, 2003). In this study, we observed that while most co-researchers described performing traditional research methods (e.g., focus groups, interviews), they did not highlight research training. Rather, both co-researchers and academic researchers emphasized how co-researchers' experiences and existing skills helped them collaborate in knowledge production, in addition to supporting their performance of diverse (traditional and non-traditional) research methods. Thus, some participants in this sample described social access to knowledge production as equally, and sometimes more important than cognitive access to traditional research methods.

While our findings reiterate the importance of this debate regarding knowledge production, rather than arguing for a particular perspective, we suggest the proposed model can be used to consider how the values of research teams and the specific characteristics of team members may drive methodological choices. For example, because many co-researchers perceived "learning" (typically about the content they were studying) as a personal benefit, some co-researchers may *want* to learn research skills because they enjoy learning, feel the skills are marketable, and/or feel a sense of pride acquiring a socially valued skill (Strnadova, Cumming, Knox, & Parmenter, 2014; White & Morgan, 2012). Alternatively, other inclusive researchers may perceive use of traditional research methods as reifying oppressive academic approaches (Janes, 2016; Zarb, 1992). Assessing the impact of traditional or nontraditional research methods on IR collaborations may be an important area of future research.

Our research suggests that research teams' values of inclusion can be operationalized through accessible structures and processes that are responsive to co-researchers' individualized and dynamic support needs. Furthermore, co-researcher collaboration and involvement may be strengthened in long-term partnerships. Researchers already conducting stakeholder-engaged research among people without intellectual disability have a deep understanding of how to be responsive to individuals' unique contexts and experiences and develop long term partnerships with community members. Notably, the proposed model has some overlap with the logic model of CBPR described by Wallerstein and colleagues (Belone et al., 2016; Wallerstein et al., 2008). Both models describe a dynamic research system that is influenced by contextual factors, individual characteristics and team-level structures and processes. Thus, we suggest many researchers in health-related fields may already be well equipped to incorporate individuals with intellectual disability in their stakeholder-engaged projects—even those not specifically attending to issues of disability. Truly inclusive research will be achieved when people with intellectual disability are not only included in "disability research," but also as partners in research regarding topics relevant to the general population, such as civic life, criminal and immigrant justice, in addition to intersectional identity issues, such as those experienced by people with intellectual disability who are also ethnic minorities and/or LGBTQ+.

Limitations and Future Research

IR with individuals with intellectual disability is rare, making it difficult to recruit participants for this study. While this study benefited from rigorous in-depth interviews and analysis, it would be strengthened by a larger and more heterogeneous (i.e., race, gender) sample. Within our sample, we observed that only one co-researcher provided a "negative" story of IR. Examples of IR in which co-researchers felt they were not truly involved would strengthen the conceptual model. Our sampling procedures may have been biased, as academic researchers may have been more likely to refer co-researchers who had continued involvement, suggesting positive experiences. Future research may benefit from a recruitment approach that does not rely on referral by academic research partners. In this study, most co-researchers were 30-45 years old. Researchers may explore the transferability of this model to co-researchers at different life stages (e.g., young adults, children, older adults), who may have different experiences and support needs. As IR is an umbrella term for the range of ways in which individuals with intellectual disability are active contributors to research, we may have arrived at different conclusions had we recruited a sample that operated under a more homogenous conceptual approach (e.g., CBPR, emancipatory research, etc.). Importantly, to validate this conceptual model, observational studies should evaluate IR teams across multiple contexts and over time to explore the proposed relationships between model components. As IR is a dynamic and complex process, understanding relationships among these components is essential to identifying the key ingredients that foster IR collaborations of co-researchers. Future research on this topic should be conducted using an IR approach to increase social validity and support people with intellectual disability to have a greater role in theorizing about their role in IR.

Conclusion

Key informant interviews with co-researchers and academic researchers informed a conceptual modeling describing how contextual factors and team-level factors and processes coalesce to foster and maintain IR collaborations with individuals with intellectual disability. We propose the following: Team-level factors, such as team members' values, drives teams' commitment to accessibility; and team's values, members' individual characteristics, and contextual factors influence the types of processes and structures teams adopt to ensure co-researcher collaboration. Ongoing commitment of co-researchers is maintained by perceived personal and societal benefits. We suggest that collaborating across multiple projects may support teams to adopt structures and processes that enable IR teams to be co-facilitated by academic researchers and co-researchers. This model may be utilized by researchers in diverse health-related fields to support inclusion of co-researchers with intellectual disability in wide-ranging research.

Table 1. Participants study 1.

	Initial Sample		**Triangulation sample**	
	Co-researchers	*Academic researchers*	*Co-researcher*	*Academic researchers*
Gender identity				
Female	2	5	1	3
Male	3	0	0	0
Non-binary, other gender identity	0	0	0	0
Location of research				
United States	2	2	1	1
Western Europe	3	3	0	1
Australia	0	0	0	1
Racial/ethnic identity				
White	5	4	1	3
Non-white	0	1	0	0
Average years of experience with IR (range)	5.3 (3.5-8.0)	15.8 (4-35)	2.3[a]	12.3 (5-20)

[a] No range presented; n = 1

Fostering and maintaining inclusive research collaborations with individuals with intellectual disability

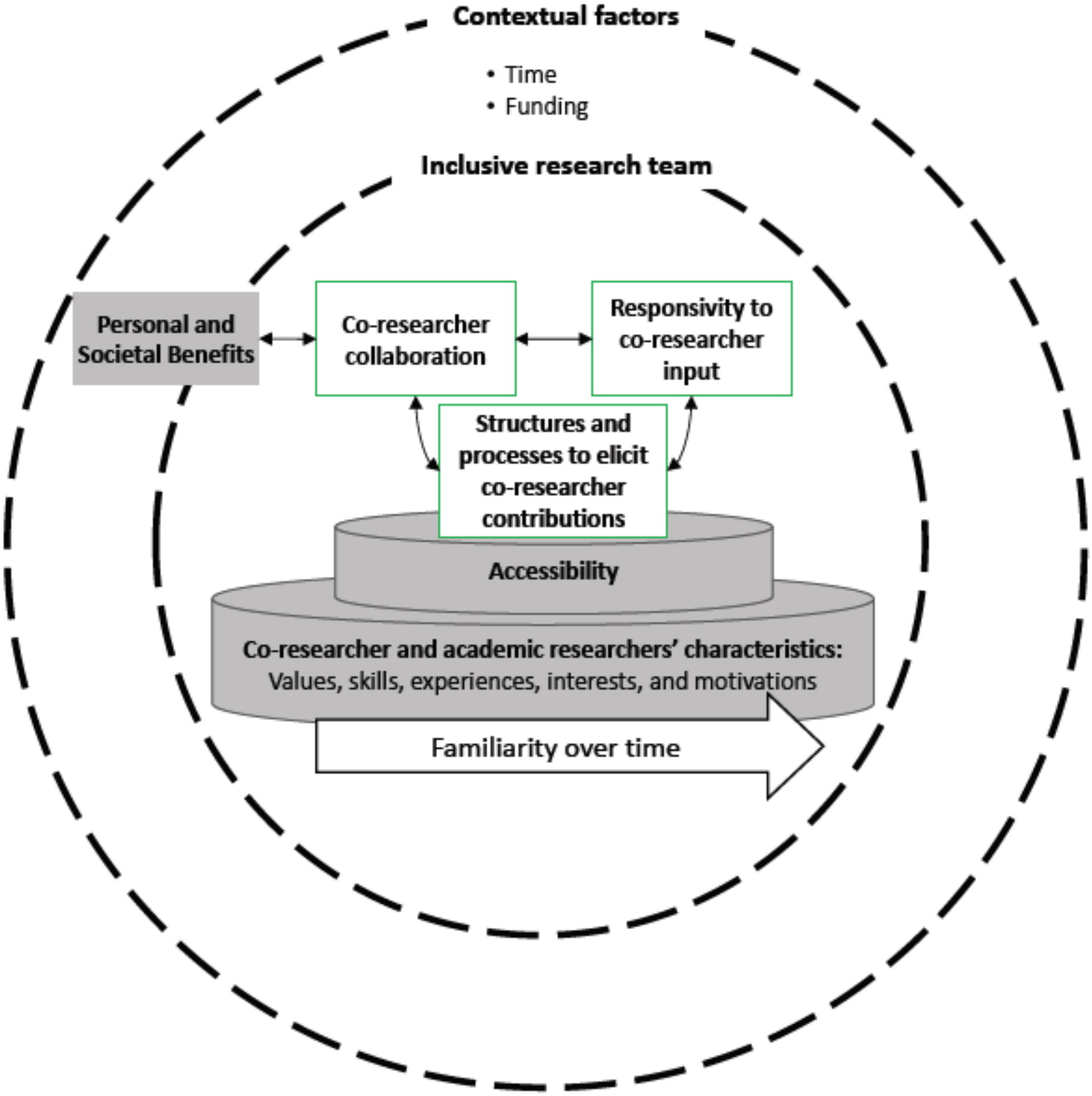

Figure 1. Model describing how contextual factors and team-level factors and processes coalesce to foster and maintain inclusive research collaborations with individuals with intellectual disability.

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STUDY 2

Stakeholder-driven approach to developing a peer mentoring intervention for young adults with intellectual/developmental disabilities and co-occurring mental health conditions

Abstract

Background: Young adults with intellectual/developmental disabilities and co-occurring mental health conditions (IDD-MH) experience significant health and quality of life disparities. Barriers to services include limited transportation, stigma associated with mental health services, and lack of professional knowledge about this population. Peer-delivered interventions, such as peer mentoring, may be one solution to these barriers. We conducted preliminary research needed to develop a peer mentoring intervention that meets the unique needs of young adults with IDD-MH.

Methods: We used a stakeholder-driven approach, in which we partnered with 3 young adults with IDD-MH and a 7-member advisory board. In addition, we conducted focus groups with mental health clinicians (*n*=10), peer providers (*n*=9), and transition specialists (*n*=20) to identify the desired intervention outcome and features and content that may facilitate these outcomes.

Results: Stakeholders endorsed using a combination of e-mentoring and in-person mentoring to facilitate the valued outcome of identifying and utilizing leisure activities as coping strategies. Stakeholders described how relationship-driven and outcome-driven actions could be used by mentors to operationalize a mentee-centered approach and

facilitate outcomes. They also identified five features and content considerations relevant to the intervention: safety, mentor matching, degree of intervention structure, mentor training and support, and collaboration with mentees' support teams.

Discussion: These findings are aligned with previous research on peer mentoring and peer provider services. We describe implications for intervention development.

Introduction

Children and teens with intellectual/developmental disabilities (IDD) are diagnosed with mental health conditions 4-5 times more often than their typically developing peers (Flynn et al., 2017). These co-occurring conditions can lead to secondary health and quality of life disparities, including difficulties at work and school and reduced community and social participation (Dekker & Koot, 2003). Young adults with IDD and co-occurring mental health conditions (IDD-MH) are especially at risk of such disparities, as they report high rates of anxiety and social isolation during transition to adulthood (ages 14-22) (King, Baldwin, Currie, & Evans, 2005; Stalker, Jahoda, Wilson, & Cairney, 2011; Test et al., 2009; Wehman et al., 2014; Young-Southward, Cooper, & Philo, 2017). These cumulative stressors during young adulthood potentially exacerbate existing mental health-related symptoms and challenges (Stalker et al., 2011) and functional impairments experienced by young adults with IDD in areas such as self-care, independent and community living, and work. These cumulative risk factors highlight this population's need for services that mitigate both immediate and long-term health, quality of life, and participation disparities.

Identifying appropriate services and supports can be difficult for young adults, as services are often designed specifically for children or older adults, rather than for this unique life stage. In previous work, we found barriers to care include lack of professional training, accessible services (Intellectual/Developmental Disabilities and Mental Health Research Partnership, *under review*), and transportation, in addition to stigma associated with seeking mental health services (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011;

Rogers & Swarbrick, 2016). These barriers to services may be one reason symptoms escalate and individuals with IDD-MH are disproportionately likely to be hospitalized and placed in institutional settings (Lulinski-Norris, Rizzolo, & Heller, 2012; Lunsky & Balough, 2010; Spassiani, Abou Charca, & Lunsky, 2017). Hospitalization and institutionalization interrupt the process of transition to adulthood (Lulinski-Norris et al., 2012), including opportunities for employment and community inclusion. Furthermore, many individuals with IDD report hospitalization was traumatic and led to additional and long-term mental health symptoms and challenges (Lunsky & Gracey, 2009; Intellectual/Developmental Disabilities and Mental Health Research Partnership, *under review*, Spassiani et al., 2017). Thus, there is a pressing need for community-based interventions driven by the stated needs of young adults with IDD-MH.

Community-based intervention is considered a “best practice” for individuals with mental health conditions (Jacobson & Curtis, 2000; Repper & Carter, 2011; Vanderplasschen, Rapp, Pearce, Vandevelde, & Broekaert, 2013) and all people with IDD (Lindsay, Hartman, & Fellin, 2016). Peer mentoring is a community-based intervention approach that has been recognized for its effectiveness in supporting the health, quality of life, and participation of individuals with mental health conditions (Davidson et al., 1999; Repper & Carter, 2011; Pfeiffer et al., 2011). Based on social learning theory, peer mentoring utilizes the sharing of experiential knowledge as the mechanism that facilitates positive outcomes. It is hypothesized that learning from a peer with similar experiences can facilitate outcomes that may not occur when young adults are only provided professional support (Balcazar, Kelly, Keys, & Balfanz-Vertiz, 2011;

Davidson, Bellamy, Guy, & Miller, 2012; Dennis, 2003). This approach can also facilitate social connection that may be essential for the health, quality of life, and participation of otherwise socially isolated young adults with IDD-MH (Gidugu et al., 2015; Ryan, Kramer, & Cohn, 2016; Stalker et al., 2011). Peer supports uniquely foster social networks, normalize one's experiences, and share strategies that promoted their own recovery—all of which can promote mental health, quality of life, and participation (Balogun-Mwangi, Rogers, Maru, & Magee, 2017; Bostrom & Broberg, 2018; Foley et al., 2012; Gidugu et al., 2015; Intellectual/Developmental Disabilities and Mental Health Research Partnership, *under review*).

Peer mentoring has also been demonstrated as an effective and feasible approach to promote health and participation outcomes for young adults with IDD without mental health conditions (Kramer, Ryan, Moore, & Schwartz, 2018; Lindsay et al., 2016). For young adults with IDD, peer mentoring can address individualized goals and learning needs (Curtin et al., 2016; Lindsay et al., 2016; Schwartz & Kramer, 2017) and promote empowerment and self-determination by providing an opportunity for connection with positive role models (Balcazar et al., 2011; Bellamy, Schmutte, & Davidson, 2017; Joseph Rowntree Foundation, 2003). Although not designed for young adults with IDD-MH, these interventions have documented effectiveness for goals that may be relevant to young adults with IDD-MH, such as community participation and employment (Lindsay & Munson, 2018). Given the evidence supporting peer mentoring as an effective intervention approach for both individuals with IDD and those with mental health conditions without IDD, it may also be an effective approach for addressing health, quality of life, and participation for young adults with IDD-MH.

Prior to developing an intervention for young adults with IDD-MH, it is critical to understand more about this population's unique needs (Wight, Wimbush, Jepson, & Doi, 2016). Research on peer providers[5] working with individuals with mental health conditions without IDD has identified specific factors that support positive outcomes, such as relationship building, providing practical and emotional supports, and experiential learning (Gidugu et al., 2015; Solomon, 2004). While these factors may also be important for young adults with IDD-MH, it is possible that they need to be implemented differently for young adults with IDD-MH who experience cognitive impairments greater than those typically experienced by individuals with mental health conditions without IDD. Additionally, most peer support research has been conducted with adults, who may have different goals than young adults with IDD, due to the difference in life stage and experiences.

To develop a socially valid peer mentoring intervention responsive to the unique needs and goals of young adults with IDD-MH, I engaged with a team of three young adults with IDD-MH and an advisory board composed of three self-advocates with IDD-MH and four professionals with expertise in clinical services. Engagement of young adults with IDD-MH throughout the intervention development and testing process supports the development of an accessible peer mentoring approach, grounded in the

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[5] A peer provider is someone "who uses his or her lived experience of recovery from mental illness and/or addiction, plus skills learned in formal training, to deliver services in behavioral health settings to promote mind-body recovery and resiliency" (SAMHSA-HRSA).

stated needs of young adults with IDD-MH (Cargo & Mercer, 2008; Nicolaidis et al., 2011). To ensure that the peer mentoring intervention incorporates clinically effective strategies, we also conducted focus groups with several stakeholder groups: peer providers, mental health clinicians, and transition specialists; all of whom have worked with individuals with IDD-MH. These stakeholders' clinical training and experiences may provide valuable insights about strategies that would promote successful relationships development and achievement of desired outcomes within the context of peer mentoring. This research addressed three objectives:

Objective 1: Identify the outcome that a peer mentoring intervention for young adults with IDD-MH should address.

Objective 2: Identify a feasible and potentially effective delivery format for a peer mentoring intervention for young adults with IDD-MH.

Objective 3: Identify the features and content considerations for an effective and feasible peer mentoring intervention for young adults with IDD-MH.

Methods

Participants

Young adult research team and advisory board. To address these objectives, in addition to focus groups, we also involved a young adult research team (YRT) and advisory board. The YRT members were selected based on the recommendation of staff from a local public high school. All prospective YRT members completed a job interview. At the time, the YRT included three young adults (2 male, 1 female, average age: 19.4 years); all had diagnoses of autism spectrum disorder and anxiety and/or depression. The YRT met for 2 hours every week (work is ongoing) and members were paid hourly. Meetings were made accessible, using a range of strategies described in the literature (Kramer & Schwartz, 2018; McDonald & Stack, 2016; O'Brien, McConkey, & García-Iriarte, 2014).

Advisory board. The advisory board included three young adult self-advocates with diverse intellectual/developmental disabilities and mental health conditions from across the United States with whom we had previously partnered, a parent of a young adult with IDD-MH, and researchers with expertise in this population and/or peer delivered approaches for people with mental health conditions without IDD-MH (*n*=7). Advisory board members met virtually and also completed worksheets to provide additional input and feedback on the meeting topics. All advisory board members received an honorarium for their time.

Focus groups. We conducted online searches to identify organizations and individual professionals serving individuals with IDD-MH. We sent IRB-approved recruitment materials to these organizations and professionals. All prospective participants were screened for the following inclusion criteria: Peer providers: at least one year of experience serving as a peer provider; experience serving as a peer provider to at least one peer with IDD; Mental health clinicians: Licensed clinician in a mental health service field (e.g., psychology, counseling, social work, etc.); at least one year of experience providing services to individuals with IDD and co-occurring mental health conditions; Transition specialists: At least one year of experience as a transition specialist, defined as any special education teacher, social worker, or other professional working in an educational setting specifically with students with intellectual/developmental disabilities ages 18–22; Experience supporting at least three students with IDD-MH. All participants completed a brief demographic questionnaire providing additional information about their training and clinical experiences.

Procedures

Collaboration with YRT and advisory board. To address objective 1, the advisory board met two times and the YRT met two times to discuss four potential intervention outcomes. The researchers selected these four outcomes from several outcomes highlighted in a previous partnership with young adults with IDD-MH (Intellectual/Developmental Disabilities and Mental Health Research Partnership, *under review*), because they felt they could be feasibly addressed in a peer mentoring context. After considering the relative importance of these four outcomes and pros and cons of addressing them using a peer mentoring format, the advisory board and YRT agreed to further explore two outcomes in focus groups with professionals: identifying leisure activities to use as coping strategies and working on community-based goals. At the conclusion of focus groups, the YRT analyzed focus group data to identify the intervention's desired outcome.

Focus groups. We used focus groups to address all objectives. Focus groups were held online (with the option to call on the phone) and facilitated by the first author, an occupational therapist with experience providing services to youth and young adults in an inpatient mental health setting (primarily without IDD) and to young adults with IDD-MH in the community. The YRT was not included in these focus groups, as we were concerned that participants may feel uncomfortable responding to questions related to potential challenges of young adults with IDD-MH serving as peer mentors if the YRT were present.

Focus groups followed a semi-structured guide (table A2), in which participants were asked about the following topics: peer mentoring format, prioritized outcomes (community based goals vs. leisure activities to use as coping strategies), relationship development, training for peer mentors, how to support young adults with IDD-MH to work towards goals and identify and utilize coping strategies, clinical reasoning and approaches (i.e., the actions and processes that may support outcomes and rationale for these approaches), and anticipated challenges.

Analysis

All focus groups were transcribed verbatim by the trained graduate research assistants and the first author. A team of three coders used qualitative analysis approaches described below.

Objective 1: Identify the outcome that a peer mentoring intervention for young adults with IDD-MH should address. The YRT and academic researcher used a modified content analysis process. This process focused on identifying preferred outcomes (i.e., leisure strategies for coping or community-based goals) and the rationale for these preferences. Content analysis is a qualitative approach used to systematically classify textual data to reach an understanding of themes and patterns (Hsieh & Shannon, 2005), such as rationale for a preferred outcome.

We took several steps to enhance accessibility of the content analysis process. First, the first author identified all data corresponding to opinions about the desired outcome of peer mentoring. Then, to prepare the data for the YRT's review, she wrote each discrete comment on an individual piece of paper. She simplified the vocabulary and text, as needed, to increase accessibly. The second author reviewed these revisions to ensure that the revisions did not change the meaning of the comment. To analyze the data, the YRT engaged in a multistep process, in which they identified if the comment was endorsing leisure strategies for coping, community-based goals, or both. Next, they identified the participant's justification (i.e., "why?"). Then, they organized the data to identify common justifications (i.e., "themes"). To decide which outcome the peer mentoring intervention should address, within each justification category the YRT identified, they counted participants' justifications. While many qualitative researchers feel that drawing upon frequency of comments may not be an effective way to draw conclusions from data, we felt that identifying the frequency of participants' comments endorsing each outcome would support YRT members to synthesize the large amount of data.

Objective 2: Identify a feasible and potentially effective delivery format for a peer mentoring intervention for young adults with IDD-MH. The advisory board discussed the peer mentoring format options (e-mentoring or in-person mentoring) during a meeting and using feedback worksheets. Concurrent with focus groups, the YRT provided input on the peer mentoring format using a series of accessible activities over the course of two meetings (figure A1). First, each member wrote responses to specific questions about feasibility (e.g., “how will [format] make scheduling peer mentoring easy/hard?”), efficacy, (e.g., “how will [format] make helping your mentee easy/hard”?), and relationship building (e.g., “how will [format] make it easy/hard to get to know your mentee?”) on pieces of paper color coded for e-mentoring and in-person mentoring. Second, they created posters with pros and cons for both formats by taping the colored-coded papers to large pieces of paper and grouping similar ideas together. Third, each member voted for the two most important pros and cons for each format by placing stickers on the color-coded papers. If a member felt strongly about a pro or con, they could use two stickers on one piece of paper. Fourth, they created additional posters that included only the pros/cons that members voted for. Fifth, they discussed the valued pros/cons to select the format that should be used.

After this process, the YRT reached consensus on a delivery format. The first author felt that their decision was aligned with feedback provided by the advisory board and the perspectives of focus group participants. Therefore, no additional analysis was undertaken with the YRT. Had the YRT’s decision not been aligned with the perspectives of advisory board members and focus group participants, the first author would have developed additional activities to help the YRT synthesize the advisory board transcript and worksheets and the focus group data. Then, the YRT would make a decision that integrated this information and their own perspectives.

Objective 3. Identify the features and content considerations for an effective and feasible peer mentoring intervention for young adults with IDD-MH. We used directed content analysis to address objective 3 (Hsieh & Shannon, 2005). Directed content analysis draws upon existing theory that "provide[s] predications about the variables of interest or about relationships among variables" (Hsieh & Shannon, 2005, p. 1281). In accordance with this approach, we developed an initial codebook by drawing upon previous research describing variables relevant to peer mentoring efficacy and feasibility, i.e., intervention delivery characteristics believed to influence outcomes (DuBois, Portillo, Rhodes, Silverthorn, & Valentine, 2011; Karcher & Nakkula, 2010). To refine the initial codebook, the first author read four transcripts to become familiar with the data. She marked passages that described intervention features and content, including mentor actions; when additional concepts not included in previous frameworks were repeated across transcripts, she defined additional initial codes (e.g., "support team collaboration" and "safety"). Next, she applied the initial codes to the same four transcripts and then examined data within each code to identify distinct, subordinate concepts. For example, under the category, "mechanism of action," she identified several distinct mechanisms of action (e.g., prompting, experiential learning). These distinct subordinate concepts were defined as additional codes. The revised codebook was then used to code all transcripts. After coding all transcripts, the primary coder reviewed all coded data, organized by code. Within each code, she labeled the main idea of each data chunk to identify additional codes and/or refine code definitions, as needed. In consultation with the second author, the primary coder organized the codes into superordinate categories (i.e., "themes") to describe intervention features and content stakeholders expected to be feasible and effective. To evaluate the salience of these themes, codes describing each theme were then applied to the full dataset by the primary coder. A second coder (a trained undergraduate researcher) applied codes representing each theme to the 50% of the data. Then, both coders and second author reviewed all data coded under each theme to ensure that these themes adequately captured the previously coded subordinate categories. After this review, the coding team decided that no further coding revisions were necessary.

Findings

Participants

Participants (henceforth referred to as "stakeholders") are described in table 2 (total *n* = 39). Briefly, we held four focus groups with mental health clinicians and two individual interviews (*n* = 10); two focus groups with peer providers (*n* = 9); and four focus groups with transition specialists (*n* = 20). Stakeholders were highly experienced. The average years of experience for mental health clinicians was 19.8 years (sd = 10.4) and 10.2 years (sd = 7.7) for transition specialists. Peer providers had an average of 6.8 years (sd = 9.3) working as a peer provider, and reported a wide range of experience supporting people with IDD-MH, ranging from 5 consumers to "over 450" (in group and/or other professional settings).

Objective 1: Identify the outcomes that a peer mentoring intervention for young adults with IDD-MH should address

We identified five themes related to why stakeholders had preferences for specific outcomes: people need help with the targeted outcomes, the outcomes promote community participation and relationships, one outcome is easier, one outcome is more important. We identified that more comments endorsed leisure activities for coping than community-based goals. Upon further evaluation, we identified that the reason more comments endorsed leisure activities for coping was because stakeholders felt young adults need to acquire coping skills prior to beginning community-based goals (table 3). As a result, the team decided to address leisure activities for coping. Given stakeholders' emphasis on community participation, we agreed that mentors should encourage exploration of community-based leisure activities.

Objective 2: Identify a feasible and potentially effective delivery format for a peer mentoring intervention for young adults with IDD-MH

Focus group participants,[6] the advisory board, and the YRT all felt that a combination of in-person and e-mentoring would be most responsive to the individual needs and preferences of young adults with IDD-MH. Importantly, all stakeholders felt that the optimal peer mentoring format would vary based on individuals' preferences and proficiency with and access to technology. Stakeholders felt that e-mentoring could not replace in-person interactions, but that it could be a useful tool, especially for individuals who may have social anxiety: "Someone could be anxious…maybe start off slowly - with a text or phone call" (PP-unidentified).

The advisory board triangulated this finding. One young adult member shared:

> Beginning with e-mentoring could help both parties get comfortable with interacting…However, ultimately I believe that the best mentoring relationships are fostered out in the real world, because it allows for a more direct kind of

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[6] Quotes are attributed to group participants by their professional background: PP: peer provider, MHC: mental health clinician, TS: transition specialist.

> connection. The mentor and mentee can take on whatever challenge or goal the mentee is working on *together in real time*.

Stakeholders also felt that e-mentoring could be used to keep in touch between mentoring sessions and would be easy to schedule. For example, an advisory board member who is a parent of a young adult with IDD-MH shared, “It’s always easier to schedule a call or a videochat, because you don’t have to include travel time or time to get ‘dressed up.’” The YRT agreed that an advantage of e-mentoring is that it “can take place from wherever one is” and they “wouldn’t have to arrange a place to meet.” Stakeholders emphasized the usefulness of e-mentoring, primarily texting and phone calls, as a way to stay in touch between sessions. For example, one peer provider shared:

> [Texts are] absolutely another tool that is open…they may be in a spot where they can't actually vocally talk to us, they could be waiting for an appointment sitting on the bus…I don't believe it can replace the face to face, but they're going to be like it's a certain times where they just need that quick reassurance—“hey I'm about to walk in and do a job interview,”… and you can send back like a word of encouragement (PP3).

A transition specialist thought that incorporating e-mentoring could be a way to stay engaged and reflect on the mentoring session, as mentees could:

> Go home and Snapchat, or text…to say, “you know, wow, I had a really good time,” or, “hey, next time, you know, why don't we do this or that,” and so that they can kind of reflect back on what they were doing (TS9).

Yet, several stakeholders noted concerns about boundaries being crossed if mentors and mentees heavily use electronic communication, noting that someone could “get a text in the middle of the night on their personal phones” (PP4). Finally, the YRT expressed concerns about e-mentoring related to poor internet connections and being able to see each other. When the YRT considered the pros and cons of peer mentoring and e-mentoring, they elected to use a combination. They decided to start with e-mentoring, because it is easier to schedule and because they could get support more easily with this format. The YRT decided to eventually transition to in-person mentoring so they could do activities with their mentees. The timing of this transition would depend on the mentee’s preference. This approach was supported by an advisory board member’s comment: “In general my students would prefer virtual first—but then followed up with some kind of face-to-face contact.”

Objective 3: Identify the features and content considerations for an effective and feasible peer mentoring intervention for young adults with IDD-MH

Several features described by stakeholders described the importance of the mentor’s role. Therefore, we first present mentor actions, and then present additional features and content suggested by stakeholders.

Mentor actions. Stakeholders believed that mentors should use a mentee-centered approach to support mentee outcomes. This approach was characterized by the idea of “meeting [mentees] where they are at,” in that mentoring interactions and activities should be individualized to the mentee’s goals, interests, skills, health status, motivations, and resources. Within a mentee-centered approach, stakeholders described mentors using relationship- and outcome-driven actions.

Relationship-driven actions. Relationship-driven actions included those that support the mentor and mentee to develop trust and rapport. The three relationship-driven actions emphasized by stakeholders were: sharing experiences, normalizing actions, and defining roles and boundaries. First, stakeholders described the importance of the mentor and mentee sharing experiences. Stakeholders believed that engaging in mutually enjoyable activities would facilitate the rapport and trust needed to address more personal or emotionally-laden outcomes. For example, one transition specialist shared, “I think any opportunity to do an activity together, where you're being active, helps actually speed up that connection process” (TS8). Supporting this assumption, several peer providers shared stories about how peer providers used shared experiences to build rapport. For example, “We were playing music, I would subtly begin to talk to them and they would begin to talk among each other. And we had the most amazing conversation…It was really a nice way to get them to trust me, for them to trust each other” (PP6).

Second, stakeholders described normalizing actions that helped the mentee feel there are “others like me.” Normalizing actions have been well documented as an important therapeutic tool used by peer providers (Gidugu et al., 2015; MacLellan, Surey, Abukakar, & Stagg, 2015). Normalizing actions include those that identify how one’s experiences and emotions are within typical human experiences and emotions. Stakeholders believed these actions would foster rapport and trust, while also potentially leading to secondary outcomes, such as increased confidence and a decrease in feelings that “nobody can understand [me]” (TS14). The two primary normalizing actions described were validation and therapeutic self-disclosure. Validation included conveying respect for and acknowledging the veracity of another person's experiences and/or perspective (Kielhofner & Forsyth, 2008). This can take the form of sharing an understanding of a situation: "Saying to him, 'yeah it stinks. And this is awful. And I hate it when it happens to me too'" (TS11) or explicitly sharing a similar experience: "When they struggle…the peer mentor may have said, 'you know, I felt that way last week. This is what it felt like to me'" (MHC13).

Aligned with literature from peer providers, stakeholders emphasized mentor self-disclosure as a potentially effective normalizing action. Self-disclosure refers to sharing one's own identity and experiences as a person with IDD-MH challenges (Marino, Child, & Campbell Krasinski, 2016). Stakeholders shared: "As a peer, it's okay to be vulnerable and transparent. A lot of times, that's how people can relate to you if you're vulnerable or transparent with your lived experience" (PP1); "I think it's very important for people to tell their stories. And how that story, you know, can help assist another person…I've seen that really kind of build relationships among peer mentee kind of situations" (TS11). However, stakeholders also emphasized the importance of "knowing what is appropriate disclosure" (MHC12) and differentiating "am I sharing this because it's about me, or am I sharing because I think it's going to benefit [the mentee]?" (MHC10).

Third, stakeholders described actions related to role definition. This includes clearly defining the mentor's and the mentee's roles, including boundaries for frequency and type of communication and the content that could be discussed. Stakeholders varied in whether these boundaries should be set collaboratively or by the peer mentoring intervention. Setting clear boundaries “so that they're both aligned with their expectations of what the relationship is,” (MHC13) can lay the foundation for the relationship, by helping “set up that understanding…and expectations for the peer relationship” (MHC12). Stakeholders discussed how defining the role of mentors and mentees was important, given the unique nature of the relationship: “You’re being a friend, but you’re also on a different level here. And so you have some responsibilities that the [mentee]...does not have” (MHC11). Several stakeholders, especially peer providers, emphasized the importance of the mentor understanding that while they may have training and specific responsibilities, it is important to support mentees’ autonomy and honor their lived experiences and expertise: “You’re equal…you’re not directing or telling them what to do…just being there-not just for support, but just to listen carefully and mainly use that as your stepping stone to guide you with what their needs are” (PP10). Having and consistently following through on clear boundaries, expectations, and a collaborative relationship all can foster trust between mentors and mentees.

*Outcome-driven actions***.** Stakeholders described three types of outcome-driven actions mentors could use to support outcome achievement: providing cognitive supports, direct instruction, and supporting self awareness. First, stakeholders described cognitive supports, defined as, materials, prompts, and/or information that supports mentees’ cognitive processes (e.g., memory, attention, executive functioning, self-regulation, etc). These supports were essential for supporting generalization to everyday life, because stakeholders felt “[this] population in particular has difficulty carrying it out in the moment, because they’re experiencing emotions that kind of shut down their memory and their ability to access that information" (MHC1). Stakeholders described diverse supports, including using checklists, reminders, visual and verbal cues to help mentees use coping strategies:

> I developed the checklist of something she could…when something's bothering her these things she could do. (MHC1)
>
> We…developed a toolbox of strategies that he felt would help him to deal with his anxiety or with his anger, and the toolbox did not remain stagnant…They were written on cards...we had these different coping strategies on a ring that he wore with his badge that he had for work. And if he was having an issue, he could look at his ring. (TS17)
>
> Literally put sticky notes…around the house…are you deep breathing today?...Whatever the person comes up with…sometimes that can be really helpful because, it's a reminder. (PP4)

Direct instruction, using a range of instructional strategies, was also described as critical for promoting outcomes. Stakeholders shared the belief that "[mentees] need to have the strategies in order to use them…So the important thing is to teach it first" (MHC1). Mentors could provide direct instruction by teaching, suggesting courses of action, and creating opportunities for experiential learning/practice. Direct instruction could also include setting up opportunities for experiential learning. One peer provider shared how experiential learning has been an effective approach with peers: "While I'm over there, I'll go—'okay, let's do a five minute meditation,' and she'll go, 'ok'" (PP4). Several stakeholders described how role play could be used to practice skills and/or responding to challenging situations. Another important component of direct instruction was sharing ideas for courses of action: "Saying, 'oh, I noticed that you really like to color or draw,' and just point out those things in case they hadn't thought of it before" (TS19). Sharing ideas for courses of action includes breaking down goals into smaller steps: "If somebody has a job as their goal, but they're not quite ready to go out, then we…tal[k] about the step back with the meeting steps. What do you have to do to get a job?....See what things are available, and then build smaller goals to get there" (PP10). Herein, stakeholders believed that mentors could use a range of direct instructional approaches to promote mentee outcomes.

Supporting self-awareness through psychoeducation and self-monitoring were considered critical roles of mentors to support generalization and carryover. Supporting self-awareness includes helping mentees understand their mental health condition, for example, "You teach them what are your warning signs. When you start to feel a pit in your stomach or when you start to not sleep well, there are the signs of your depression. Naming it for them, that's huge, just having them explain it, having them understand what it is" (MHC9). Helping mentees become more aware of their mental health condition may serve as a foundation for self-management. Stakeholders also described how mentors could help mentees learn how to identify their emotions to help them initiate use of coping strategies and evaluate their efficacy:

> Oftentimes it's just getting into the habit of...what am I feeling right now, or looking at that feeling face and then rating it on a particular scale, and just getting into the habit of when I'm in this particular state of mind, at this particular rating

> intensity, then I’m gonna use my coping skills. (MHC6)

Once mentees are using the coping skills, mentors could support mentees to “indicate how satisfactory it was, maybe a color coding or whatever…as far as their own monitoring of it” (TS24). Stakeholders emphasized that self-monitoring may include the use of cognitive supports, such as visual prompts, and that self-monitoring strategies needed to be practiced with the support of the mentor.

Intervention Features and Content. Stakeholders described five additional components they believed would support mentees to achieve outcomes: support team collaboration, mentor/mentee matching, safety considerations, mentor support, and degree of structure.

First, stakeholders emphasized the importance of mentors collaborating with their mentee’s support team, including parents, teachers, support staff, etc. This support was essential for ensuring generalization and follow-through. For young adults, the role of parents, in particular was emphasized: “If the family isn't on board, you get kind of lost” (MHC8); “You have to know how to join with the family, and gradually, gently shift how they see things…we absolutely have to have the family on board” (MHC3); “Their parents would have a very big voice in their life. And so that, that is a consideration” (PP4). Others described a broader support network. For example:

> And then things can fall apart because they don't have the support and getting to their meetings or being able to meet with their peer mentor in person….More than likely they're not driving. So they are going to be depending on other people. So you're going to also have to deal with those adults schedules as well. And then

who's supporting them. (TS17)

Second, stakeholders had questions about how mentors and mentees would be matched. There is a wealth of research on this topic, yet a lack of consensus on best practice (for a review, see Pryce, Kelly, & Guidone, 2013). Stakeholders felt that mentors and mentees should be matched based on similar interests and experiences. For example, one transition specialist shared, “There’s some benefit in doing some interest inventories. So there’s some matching…more of an opportunity for shared enjoyment” (TS24). Another transition specialist added that matching people based on interests could help mentees “bond over that and continue to build a relationship” (TS5). Some stakeholders also noted the importance of communication style: “It goes back to like, that communication style, or just, you know, two people having the same interest doesn't mean that they're going to click” (TS12). Because matching can be difficult, some thought it may be helpful to have a “trial” period and/or for mentors/mentees to have an opportunity to choose each other and have an opportunity to “switch it up and try somebody else” (MHC11) if the match is not going well.

Third, stakeholders emphasized safety considerations. They acknowledged that young adults with IDD-MH may share thoughts about self-harm, suicidality, and/or harm to others. Most stakeholders felt it was essential for mentors to be prepared for how to respond if this occurred. One mental health clinician shared, “What do you do when somebody’s telling you that they hurt themselves. That’s an issue. Or if somebody is suicidal” (MHC1). Stakeholders felt there should be a way to quickly respond to concerns about safety: “If the mentee has anything self-harming or anything concerning, that really needs to be address quickly" (TS6). Other safety considerations were understanding boundaries in the relationship, to ensure emotional safety and mentor and mentee awareness of words, topics, and experiences that may trigger memories of past traumas.

Fourth, stakeholders felt it was imperative that mentors feel well-supported. They felt that mentors should have training about their role and how to respond to differences in opinions, challenging emotional disclosures, and discussions of self-harm. Stakeholders felt that regular supervision and the ability to check in with a supervisor if uncertain was critical, especially about safety concerns. Accordingly, "knowing that they have received training and that is something comes up there is somebody else there that is able to guide them" (MHC11), was critical for them feeling comfortable referring an individual for peer mentoring. Appropriate training and tangible tools (e.g., flowcharts and checklists) were other ways to support mentors. Stakeholders felt that training should address, "how to create relationships" (TS8), manage "personality conflicts and the social emotional pieces," (TS-unidentified) in addition to identifying safety concerns (as described above).

Finally, there was a tension between the value of a structured program and creating a relaxed environment for mentees. Several stakeholders felt that the dyad would develop stronger relationships and trust if there were no established expectations for conversation topics and activity performance. Therefore, these stakeholders felt less structure would be beneficial, especially early in the relationship. One transition specialist shared:

> I love no structure…all our programs have to be scheduled and structured to the

> point where, you know, we're giving kids scripts and checklists and everything is sort of rehearsed and predicted and laid out. And you know, I am a huge advocate for throwing that all out the door…. I think that some kids with intellectual disabilities, and even mental health - we always have to keep them busy and they always have to have structured time, so that there's no room to kind of screw up or, or be anxious or you know whatever. That we predicted this and we planned this all out for you and you can't screw up again. I go back to [being] their authentic selves (TS9).

However, others felt that young adults with IDD-MH may benefit from and feel more comfortable with structured and predictable mentoring sessions. For example, one mental health clinician commented, “I find that for this population, having something pretty structured like CBT and a little bit more directive—very here and now—can be helpful. That can be kind of containing…So drilling down what to expect and having those parameters ahead of time, I have found has worked well” (MHC6). Stakeholders also acknowledged that increased structure would help mentors, as they could prepare for mentoring sessions with sample scripts and/or checklists.

Discussion

This study describes a stakeholder-driven approach to developing a peer mentoring intervention for young adults with IDD-MH. As part of the intervention development process, we collaborated with the YRT and advisory board, and conducted focus groups to identify the outcome, delivery format, and features and content for an effective and feasible peer mentoring intervention for this population. The findings from this study suggest that stakeholders believe peer mentoring for young adults with IDD-MH may share many similarities with that of peer support for individuals with mental health conditions without IDD. Research on peer providers' roles and activities has identified several key areas of support that also emerged in this study: social, emotional, and practical (e.g., "informational", "tangible") supports (Dennis, 2003; Gidugu et al., 2015; Milton et al., 2017). Also aligned with the literature on peer support in mental health, stakeholders in this study emphasized the potential efficacy of normalizing actions (e.g., disclosure, validation) to help individuals feel they are not alone (Gidugu et al., 2015). Thus, the peer mentoring relationship itself may be an important mechanism of change for reducing social isolation (Miyamoto & Sono, 2012). The similarity in anticipated features and content demonstrates the potential for peer mentoring interventions for young adults with IDD-MH to draw upon existing models from the peer support literature from other populations (e.g., Cook et al., 2012; Kohut et al., 2016). These models will likely need to be adapted to meet the cognitive support needs of young adults with IDD-MH. This may involve the inclusion of additional and/or different cognitive supports (e.g., visual cues, checklists) and modification of concepts to ensure they are accessible to young adults with IDD-MH (Kramer et al., 2018). In this discussion we discuss the importance of two essential components of peer-delivered interventions: experiential learning and therapeutic use of self.

Experiential learning is a hallmark of peer support services (SAMHSA-HRSA, 2015) that focus group stakeholders suggested would promote outcomes for young adults with IDD-MH. Stakeholders described the importance of mentors and mentees actively engaging in activities together for two purposes: learning skills and strengthening the mentoring relationship. Experiential learning is an effective learning strategy for young adults with IDD and supports generalization (King, Baldwin, Currie, & Evans, 2006). This instructional approach is effective because real life learning experiences reduce the need for abstract and future oriented thinking and enable identification of challenges that may be unanticipated by a didactic curriculum. In addition, this approach is more conducive to individualized approaches based on the needs and goals of young adults and can provide opportunities to experience "real life" success, thereby increasing self-efficacy (Bandura, 1982). During the experiential learning process, mentors can provide emotional and practical support to promote motivation and success, in addition to supporting mentee reflection to facilitate generalization to other contexts (Kolb & Kolb, 2009). In addition, mentors with IDD may feel more confident delivering an intervention that draws upon experiential learning than one that uses a didactic approach. Experiential learning provides natural opportunities that require less verbal, communication, and cognitive demands compared to a didactic approach that may require mentors to remember specific content knowledge or navigate specific components of a written curriculum. Finally, research supports stakeholders' expectation that engaging in shared activities may promote connection (Rossetti, 2011).

The stakeholders in this study highlighted the importance of relationship-driven actions, which together may be described as "therapeutic use of self." Therapeutic use of self refers to, "the therapist's conscious efforts to optimize the therapeutic relationship" and is a "conscious and purposeful process that reflects the understanding of the client and planned strategies of interaction" (Taylor, Lee, & Kielhofner, 2011, p. 6) Therapeutic use of self can include using empathy, humor, validation, and the provider's own personality and experiences to enhance the therapeutic alliance and promote clients' feelings of acceptance (Arnd-Caddigan & Pozzuto, 2008; Reupert, 2007). The association between effective "therapeutic use of self" and treatment outcomes has been reported not only in the peer provider literature, but also in diverse fields, ranging from social work to occupational therapy (Dewane, 2006; Leach, 2005; Palmadottir, 2003). A recent qualitative metasynthesis describing the experiences of peer support workers in diverse health fields identified that actions related to, "therapeutic use of self by the [peer provider] as the core component of their effectiveness" (MacLellan, Surey, Abubakar, & Stagg, 2015, p. 2).

Effective therapeutic use of self requires high level social-emotional and communication skills and the ability to adapt to different types of people (Arnd-Caddigan & Pozzuto, 2008). Mentors and mentees with IDD-MH may have individualized ways in which they communicate, interpret, and respond to emotions. However, given that communication is at the center of therapeutic use of self, for young adults with IDD-MH, it may be possible that it is more important to match based on preferences for communication and interpersonal interaction style. For example, individuals with autism spectrum disorder often find that it is easier to connect with other people with autism, because the autistic community may implicitly share its own social norms and communication styles (Bagatell, 2010). This approach to matching is in contrast to research that has primarily described demographic (e.g. gender and race) and interest-based approaches to matching (DuBois et al., 2011; Pryce et al., 2013), in addition to the perspectives of stakeholders in this study who emphasized the importance of shared interests.

One way in which therapeutic use of self may be unique in peer-mediated interventions compared to traditional clinical practice is the centrality of self-disclosure. While self-disclosure may be considered inappropriate in many therapeutic relationships, for peer providers, the inclusion of these actions is considered an essential tool related to therapeutic self (MacLellan et al., 2015; Marino et al., 2016; Miyamoto & Sono, 2012; SAMHSA, 2015). However, for self-disclosure to have these therapeutic effects, mentors must be able to describe their experiences and diagnoses using a positive approach (Marino et al., 2016). This may only be possible if individuals have a positive sense of identity as a person with IDD-MH. Therefore, it is essential to support peer mentors to cultivate a positive sense of self, *in relation to*, rather than in spite of their disabilities and mental health challenges. This is no easy task, given the significant stigma associated with disability and mental health challenges. The disability rights movement, self-advocacy movement (Caldwell, 2011), and the mental health recovery movement (Leamy, Bird, Le Boutiller, Williams & Slade, 2011) offer many resources and approaches to instilling a sense of positive identity, and even pride. Furthermore, service systems can create a welcoming and affirming environment for mentors, so the implicit messages articulated by the agency are empowering and celebratory.

Implications

This study was conducted for the purposes of intervention development. Our findings clarified several components of the intervention. First, because stakeholders felt that coping strategies were a prerequisite for working towards community-based goals, we decided that the intervention will address identification and utilization of leisure activities that can be used as coping strategies. Although many solitary leisure activities may be effective coping strategies, given stakeholders' emphasis on community participation, and the documented social isolation of young adults with IDD-MH (Stalker et al., 2011), mentors will encourage mentees to explore at least one potential community-based leisure activity. Second, the peer mentoring intervention will use a combination of in-person and e-mentoring activities. Mentors and mentees will initiate contact using e-mentoring, as this format is expected to be more comfortable for young adults. Aligned with a mentee-centered approach, the dyad will work together to decide when and how to progress to in-person activities. The dyad may also collaboratively identify ways to stay in touch between in-person mentoring activities by using e-mentoring approaches (e.g., video-chat, phone, social media).

Stakeholders highlighted the importance of mentor training and support. This is aligned with previous research, suggesting that young adults with IDD can deliver a standardized peer mentoring intervention with diverse supports. However, as reported, the level of supports needed may limit feasibility of this approach in some service settings (Kramer et al., 2018).

Our next steps will include developing mentor training. Based on the focus group findings, we will develop training and supports around safety considerations, including appropriate responses to mentee disclosures of and risks for self-harm and suicidality.

While peer mentors are not mandated reporters, they will be provided with an accessible worksheet describing the steps to follow if their mentee discusses specific topics that are immediate (e.g., suicidality, self-harm, use of weapons) and non-immediate (e.g., poor sleep and appetite) health and safety concerns. To further support the safety of the mentor and mentee, during mentoring, the peer mentor's supporter will always be available by phone, and a requirement of mentoring will be that the mentee identifies two support people who can be contacted in an emergency. Training will also include strategies for setting boundaries, supporting self-awareness of mentees, therapeutic self-disclosure, and use of experiential learning activities. Challenges with boundaries are consistently identified in the peer provider literature (Gidugu et al. 2015; Miyamoto & Sono, 2012; Repper & Carter, 2011) . These challenges can be related to balancing the professional relationship, a desire for a non-hierarchical relationship and therapeutic actions, such as self-disclosure and experiential learning that may be more familiar to peer providers in the context of friendship (Repper & Carter, 2011). Additionally, previous research suggests that when young adults with IDD serve as mentors, they may have challenges understanding how to integrate their roles as a "teacher" and a "friend" (Schwartz & Kramer, 2017). Training will emphasize the unique role of mentors and how they can develop rapport, trust, and a sense of connection, within the bounds of their professional role. This training may draw upon existing models used to train peer providers without disabilities, such as programs administered by state Departments of Mental Health services and private organizations (for more information, see the International Association of Peer Specialists: https://www.inaops.org/training-and-certification).

Limitations and Future Research

There are some notable limitations to this study. First, because there are no existing peer mentoring interventions for young adults with IDD-MH, the stakeholders who participated in focus groups did not have firsthand experience with this approach. Rather, they had similar, or related experiences. While this was a sample of very experienced professionals, their suggestions, experiences, and perspectives were based on a different clinical context (e.g. school, clinic, mentoring by a non-peer), potentially limiting transferability to mentoring delivered by a peer in the community. A related limitation is that we had difficulty recruiting peer providers, who are the stakeholder group with experiences most similar to the target context (peer mentoring). Our inclusion criteria required that peer providers have experience supporting at least one consumer with IDD and a co-occurring mental health condition. Because peer provider services are primarily accessed through mental health service agencies, it is possible that many people with IDD never access these services, due to the siloing of developmental disability and mental health department services. Future research may include individuals with IDD who have previous experiences as peer mentors or mentees in other contexts (e.g., employment, education, etc.), in addition to other types of peer support workers who may have more experiences with this population, such as peer service providers working at Centers for Independent Living. Despite these limitations, an important strength of this study is its use of an inclusive research approach. Throughout, the input of the YRT and advisory board guided the research and analysis process; their agreement with the perspectives of focus group participants helped assure us of the potential social validity of the peer mentoring approach.

Our findings also shed light on several other potential directions for research. Given the inconclusive research on mentor matching across all mentoring settings, research exploring match strength and efficacy for young adults with IDD-MH would help advance the field. This study also highlighted the importance of therapeutic use of self. Research exploring how to teach this complex skill to people with IDD may help promote peer mentoring. Prior to this research though, it is necessary to learn more about the types of interactions that may be most effective with diverse young adults, especially those who have different preferences for interpersonal interactions (e.g., customs for physical contact, personal disclosure, use of literal vs. abstract language to convey emotions) and/or come from diverse cultural backgrounds.

Conclusion

We used a stakeholder-driven approach to inform development of a peer mentoring intervention for young adults with IDD-MH. Stakeholders demonstrated a preference for an intervention that combines in-person and e-mentoring to support young adults to identify and utilize community-based leisure activities as coping strategies. Stakeholders emphasized the importance of a mentee-centered approach that could be operationalized by specific relationship-driven and outcome-driven actions. They also discussed the importance of safety considerations, mentor matching, and collaboration with mentees' support team. Stakeholders varied in their opinions about the optimal degree of structure the intervention should include. These findings aligned with previous research on peer providers supporting people with mental health conditions without IDD. Based on these findings, we propose that peer mentors with IDD-MH should receive training in facilitating experiential learning and therapeutic use of self. Instruction in these approaches may benefit from a strength-based and disability-positive approach.

Table 2. Participants study 2.

Participant demographics, % (n)	**Mental health clinicians [a] n = 10**	**Transition specialists n = 20**	**Peer providers n =9**	
Gender identity				
Female	90% (9)	85% (17)	78% (7)	
Male	10% (1)	15% (3)	22% (2)	
Non-binary/other gender identity	0% (0)	0% (0)	0% (0)	
Racial/ethnic identity				
White	70% (7)	95% (19)	78% (7)	
African American	10% (1)	0	22% (2)	
Asian	10% (1)	0		
Other	10% (1)	5% (1)		
Previous experience with peer support services[a]			Experience with individuals with IDD prior to becoming a peer provider[a]	
I have not heard about peer-led services	30% (3)	15% (3)	A family member has an IDD	33% (3)
None of my clients have received peer support specialist services	50% (5)	55% (11)	A friend has an IDD	56% (5)
I have clients without IDD who receive peer-led mental health services	20% (2)	10% (2)	I used to work or volunteer with people with IDD	89% (8)
I have clients with IDD who receive peer-led mental health services	10% (1)	15% (3)	No prior experience	11% (1)
I have worked directly with peer support specialist	40% (4)	10% (2)	N/A	
I have helped train peer support specialists	10% (1)	5% (1)	N/A	

[a] Two participants had extensive clinical and leadership experiences in providing mental health services but did not have a clinical license.

[b] Percentages do not add to 100%, as participants could select multiple options.

Table 3. Young adult research team’s analysis summary

	Frequency of theme and selected quotes	
Common justification (i.e., theme)	**Leisure activities for coping**	**Community-based goals**
This outcome comes first	13	1
	The earl[ier] on, they learn coping skills, the better as they transition (MH13). You're getting employed and…it's still going to be a stressful situation for the person because they want to do a good job. They want to own the job. They may not know the job. So they're still going to end up having to learn some type of coping strategy (PP1).	I think community-based goals can help with coping strategies (PP12).
People need additional help with this outcome	13	15
	There's often a lot of people in their life that are helping them with community-based goals…but they don't help her with identifying leisure activities. If it can be used as a coping strategy (PP4). Students that are going to a post-secondary education route…they’re a lot of the students that end up dropping out. And, because they don't have the - the coping strategies to jump from being in a secondary setting…[to]a college setting where you – where you’re independent on all levels (TS-unidentified).	If we're talking about like, a needs assessment, I feel like community-based goal might be more of a need (MH6). The schools unfortunately, have gotten to where the focus is on the graduation requirements and meeting those type of pieces…There's such a push, though, to complete those things, that those independent living skills are falling (TS20)
This outcome is easier to address	4	4 (if people have the same goals)
	I think identifying a leisure activity and coping strategies is always going to be slightly easier…you’re doing something that might seem pleasurable in the moment, that’s less anxiety provoking (MH10).	I think the community-based goals would probably be the easiest because there's so many different ways that could apply (TS23).

This outcome is easier to address (cont.)	Solely based on training - I think community-based goals would be more difficult (TS-unidentified)	
This outcome is more important	5	5
	I think [identifying and utilizing coping strategies] is the most important thing to do. Absolutely. (MH9). What's really important is to learn the individual coping strategies, because those you can use no matter what's going on in the environment around you. So I think the coping strategies are more important (PP10).	I do think that community-based goals are more appropriate just because they address, kind of, a greater need in my mind (TS20). I'd go with community-based goals, because and most of life takes place in the community (MH8).
This outcome promotes needed community participation	Both: 9	
	I've always said, treatment alone in isolation does not really help that much, you have to kind of create community, a support system, and a lot of that should be based on rather, rather than be based on their emotional needs more based on their social needs. Because I think that covers a lot of bases, to be honest (MH1). I don't know that one entry point [outcome] is better than the other entry point. But I know that…feeling connected and at like an engaged community member with a social life that feels meaningful is like the number one need for everybody we work with. (TS14) Coping strategies as someone mentioned or mechanism to get yourself confident and prepared to go out into the community at large, and so they're both important, but I don't want to lose the community-based goal—the community access, because that's going to be everything. (TS18)	

Quotes are attributed to mental health clinicians (MHC), peer providers (PP), or transition specialists (TS). Quotes in this table represent verbatim quotes from the focus groups, rather than the quotes the young adult research team worked with for analysis.

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DISCUSSION

In this dissertation, I conducted research addressing two types of social inclusion: a) inclusion in research and b) peer relationships. To address inclusion in research, I conducted key informant interviews with academic researchers and co-researchers with intellectual disability who have expertise in inclusive research (study 1). This led to the development of a conceptual model describing the contextual factors and team-level processes and factors that coalesce to foster and maintain inclusive research collaborations. To address peer relationships, I conducted preliminary research required to develop a peer mentoring intervention for young adults with intellectual/developmental disabilities and co-occurring mental health conditions (study 2). In this discussion I describe how, together, these studies shed light on approaches to fostering social inclusion for people with intellectual/developmental disabilities.

Study 1 described how to support social inclusion on a macro-level by discussing a field (research) in which exclusion of people with disabilities is often unchallenged. In this study, the importance of social inclusion at the personal level also emerged. Co-researchers described relationships as a benefit of inclusive research. They valued the relationships they made with other co-researchers and academic researchers. Thus, inclusive research provided opportunities to be included at maco- *and* individual levels. Furthermore, we observed reciprocity between inclusion at these levels: when co-researchers were involved in inclusive research (marco-level inclusion), they had opportunities for interpersonal relationships (individual level inclusion), and these interpersonal relationships strengthened and helped maintain inclusive research collaborations (macro-level inclusion). Several factors made these interpersonal relationships possible, including a shared belief in the inherent value of all people and a commitment to accessibility that engendered a sense of trust and respect.

Across both studies, two key ideas about social inclusion emerged: 1) the need for task and environmental modifications and individualized supports and 2) the importance of valuing individuals' unique strengths. Participants in both studies acknowledged that inclusion of people with intellectual/developmental disabilities in research and as peer mentors requires "extra" time and resources. Neither research nor traditional mental health service models are designed to accommodate people with cognitive and social support needs. Despite the inaccessibility of these activities, all participants spoke from a strengths-based and social model perspective, highlighting environments and tasks as barriers, *not* people with disabilities themselves. They offered creative solutions to modify environments and tasks, in addition to individualized supports, to ensure that people with diverse strengths and support needs could adopt roles as researchers and mentors. These modifications and individualized supports require time and resources, often placing the onus on people without disabilities to advocate for these diverse forms of social inclusion to be valued by service providers, academic institutions, and funding agencies.

The foundational principles of inclusive research and peer mentoring acknowledge the unique contributions of people with disabilities (Balcazar, Kelly, Keys, & Balfanz-Vertiz, 2011; Dennis, 2003; Stack & McDonald, 2014; Walmsley et al., 2018). In these contexts, the imperative to include is not only based on social justice ideals, but also a belief in improved outcomes. Including people with disabilities in research can lead to be "better science." Likewise, including people with disabilities as peer mentors may be the best way for young adults to have opportunities for validation and affirmation of their identities and experiences. In an environment increasingly driven by cost effectiveness and budgetary restrictions (Katon & Unützer, 2013), continuing to build an evidence base demonstrating these improved outcomes will be critical to justifying the additional resources required to support inclusive research and peer mentoring.

Importantly, when framing inclusion in terms of improved outcomes and cost effectiveness, it will be crucial to concurrently articulate the values and ethics that underlie the impetus for social inclusion. Social inclusion may lead to benefits not measured by typical standards for research productivity or healthcare outcomes, such as self-esteem, engagement in meaningful roles, development of an empowered disability identity, and increased community acceptance (Balcazar et al., 2011; Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998; Caldwell, 2011; McDonald & Stack, 2016). Even if the benefits of these outcomes cannot be assigned a financial value, they remain important drivers of social inclusion.

For those committed to disability rights and disability communities, the value of social inclusion is irrefutable. When supported to take on leadership roles as researchers and mentors, people with disabilities have unparalleled potential to support each other, identify new ideas, and strengthen professional practice. It is important to remember that this perspective is not universally shared. People with disabilities continue to experience oppression in their everyday experiences of exclusion, infantilization, and paternalism

(Charlton, 1998; Wehmeyer, 2013). Until these circumstances change, people with disabilities may have difficulty accessing new roles and opportunities for social inclusion—not only because they are not available, but because they may not believe it is possible. Researchers and service providers must join the disability rights movement to ensure inclusion of people with disabilities and advocate for an expanded understanding of social inclusion. Social inclusion is not limited to learning with peers without disabilities, engaging in supported employment, or living in the community with a partner. Social inclusion must also be conceptualized as having the opportunity to have an impact on and change society in diverse roles and contexts, including service provision and research that informs policy and services (Hall, 2005). The results of both studies suggest that an expanded view of social inclusion is possible, but it requires broad adoption of a strength-based approach that values disability and devotes the needed resources to making all roles available and accessible to all people.

Future research

This dissertation described two projects that are part of two larger research agendas. First, I intend to continue to unpack the factors that foster and maintain inclusive research with people with intellectual disability. Given the complexity and diversity of inclusive research and the number of systems that influence inclusive research, new methods may be needed to study how individual strategies or sets of strategies influence the involvement of people with intellectual disability. Building upon study 1, next steps may include adoption of approaches used to study complex interventions, such as process evaluation. Process evaluation includes examination of relevant contextual factors and mechanisms that lead to outcomes (Moore et al., 2015). This approach will likely require observation across diverse inclusive research contexts. Secondary data collected during the development of the peer mentoring intervention (study 2) based on the findings of study 1 may serve as pilot data for developing and exploring an appropriate approach to process evaluation. Alternately, single subject design approaches may be used to explore the efficacy of individual strategies on specific components of inclusive research, as they do not require randomization and large sample sizes. If results are replicated across multiple contexts, this may provide strong evidence for the generalizability of these strategies across diverse inclusive research contexts (Portney & Watkins, 2009).

The second study is part of a larger study, in which we are developing and conducting feasibility testing of a peer mentoring intervention for young adults with intellectual/ developmental disabilities and co-occurring mental health conditions. Two critical steps of intervention development are “identify[ing] how to bring about the change: the change mechanism and “identify[ing] how to deliver the change mechanism.” These steps typically include stakeholder involvement and incorporation of theory (Wight, Wimbush, Jepson, & Doi, 2016, p. 2). Study 2 described one of the many research activities we have taken to address these two steps. We are currently incorporating the findings with evidence and theory to develop peer mentoring activities and materials. We will gather feedback on these materials during focus groups with young adults with intellectual/developmental disabilities and co-occurring mental health conditions prior to feasibility testing. Based on the findings during feasibility testing, we will make needed revisions prior to larger scale testing. Throughout, we have and will continue to apply the lessons learned from study 1 to ensure that the young adult research team is guiding this research.

APPENDIX

Table A1. Semi-structured interview topic guides for study 1.

Content	Academic researchers	Co-researchers
Background information	-Throughout interview, probe for information about the project, including: “who,” “what,” “where,” and desired outcomes -(Also collected additional background information on the academic researcher demographic form)	-Where do you do research? -What did you do? -Who else did research with you? -What is your favorite thing you did? -What is your least favorite thing you did?
Contextual factors and team level structures and processes	*Story topics* -Example of engagement -Example of lack of engagement -How do you ensure that the research process is accessible to researchers with intellectual disability? -A time you had an idea that was different from that of the co-researchers	*Story topics* -A time research was fun -A time research was important -A time research was boring or frustrating -A time research was not very important -Example of learning a research skill -A time you had an idea that was different from that of the other researchers
	Other questions -What processes do you use to make decisions? -Is there anything you have to do or stay to encourage co-researchers to voice disagreement? -Do you use any processes to monitor the group or reflect on your role/power? -If you had to describe the most important environmental factors that support co-researchers to engage in research, what would they be?	*Other questions* -What helps you do research? -What helps you do hard research jobs? -What are the most important things the academic researchers do to support you in research? -What helps you work together? -Were you in charge of anything? -What helps you share your ideas and opinions when you are doing research?

Table A2. Semi-structured focus group guides for study 2.

Question/Prompt[a]	**MHC**	**TS**	**PP**
Do you think it is more important to address community-based goals (e.g., community participation, work, education) or identifying a leisure activity that young adults can use as a coping strategy? Why?	▨	▨	▨
Describe a time you supported a person with IDD-MH to work towards a community living, work, or school goal. -What worked? What didn't work? -What should be incorporated into the peer mentoring intervention to promote achievement of community-based goals?	▨	▨	
Describe a time you supported a person with IDD-MH to identify and utilize a coping strategy. -What worked? What didn't work? -What should be incorporated into the peer mentoring intervention to support young adults to identify and effectively utilize leisure activities as a coping strategy?	▨	▨	
Do you use any specific theories/frames of references when working with young adults with IDD-MH? -What are they? Why do you use this theory/frame of reference?	▨		
What do you anticipate being some advantages of a peer mentoring intervention for clients with IDD to address: Community-based goals; Coping strategies?	▨	▨	
What do you anticipate being some challenges of a peer mentoring intervention for clients with IDD to address: Community-based goals; Coping strategies?	▨	▨	
Have you ever had a client involved in a peer mentoring program? What about that experience do you think supported them?	▨	▨	
Why would you refer a client with IDD and a co-occurring mental health condition to a peer mentoring program? -What factors would influence whether or not you selected a specific program/made this referral?	▨	▨	
What do you think supports young adults with IDD-MH to form relationships with each other? -How long do you think the mentor/mentee pair would need to get to know each other before working on goals? -What types of interactions do you think are most effective for fostering peer relationships? What should peer mentors be doing to form a relationship with their mentee?		▨	

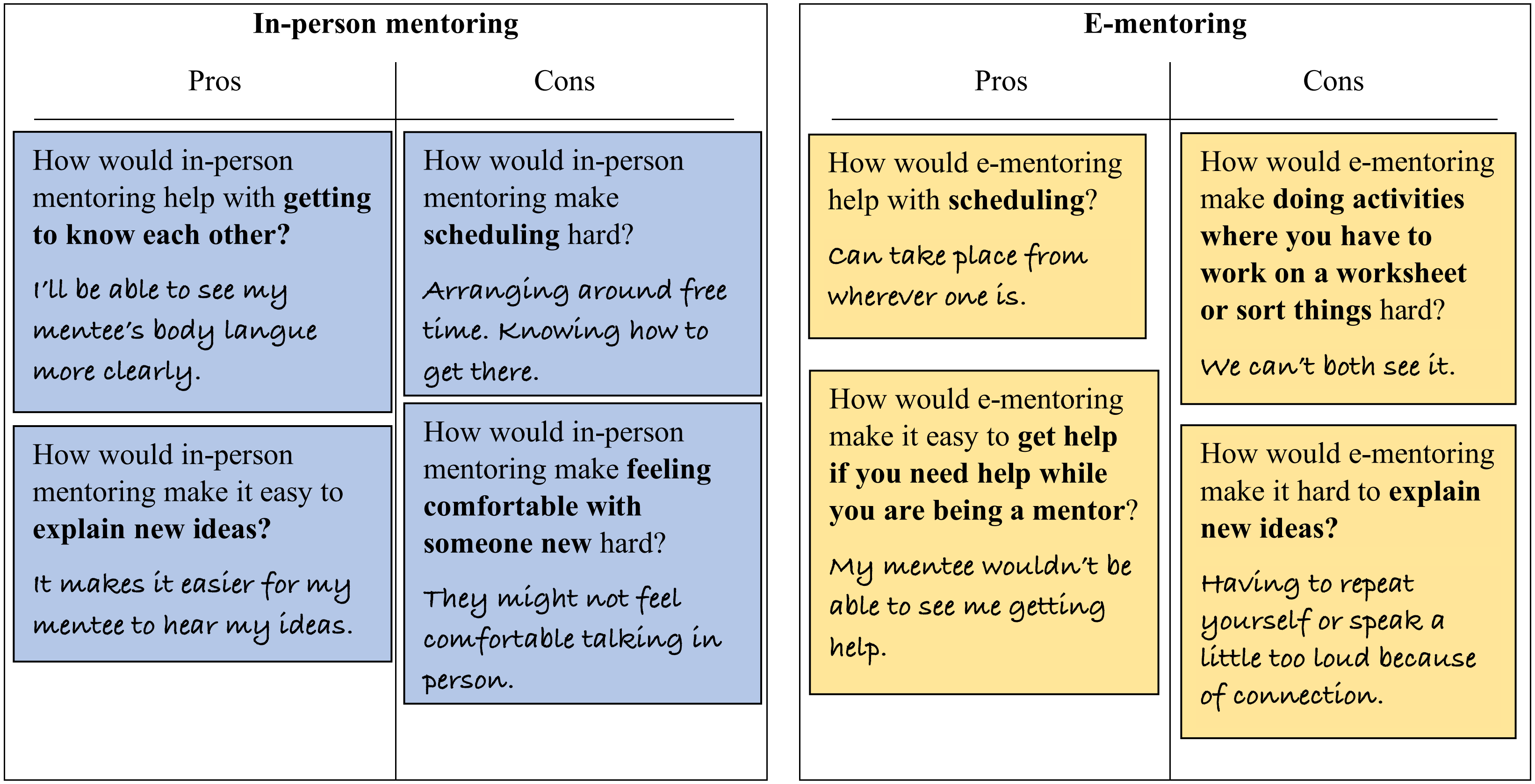
Do you think it would best for peer mentoring to be conducted in person or remotely (e.g., phone, skype)?		▨	▨
What advice would you give to another peer support specialist providing support/services to a client with IDD? -How is providing peer support services different form providing peer support services to someone without IDD?			▨
Research suggests peer support specialists provide three main types of support: •Practical supports (e.g., providing information, helping people access resources) •Social support (e.g., helping decrease social isolation through activities) •Emotional support (e.g., be empathetic, encourage, validate, etc.) Think of a time you supported someone with IDD. How did you…. -Provide social support? -Provide practical support? -Provide emotional support? -Support them to reach their goals? -Help them think of, identify, and/or use coping strategies?			▨
Research suggests peer support specialists need a lot of skills. Some of these are: •Communication skills •Social/emotional skills (e.g., validating other people, expressing empathy, using self-disclosure to help someone else) •Having knowledge (e.g., about resources, about mental health conditions, etc.) What helped you learn these skills?			▨

[a]Shading indicates question was asked to this stakeholder group: MHC: mental health clinician, TS: transition specialist, PP: peer provider

A.

• How would in-person mentoring help with **scheduling?** • How would in-person mentoring help your mentee **feel comfortable with someone new?** • How would in-person mentoring help your mentee **do activities where you have to work on a worksheet or sort things?** • How would in-person mentoring make it easy to **get help if you need help while you are being a mentor?** • How would in-person mentoring help with **getting to know each other?** • How would in-person mentoring make it easy to **explain new ideas?**	• How would in-person mentoring make it hard to **schedule?** • How would in-person mentoring make **feeling comfortable with someone new** hard? • How would in-person mentoring make **doing activities where you have to work on a worksheet or sort things** hard? • How would in-person mentoring make it hard to **get help if you need help while you are being a mentor?** • How would in-person mentoring make **getting to know each other** hard? • How would in-person mentoring make it hard to **explain new ideas?**

B.



In-person mentoring		E-mentoring	
Pros	Cons	Pros	Cons
How would in-person mentoring help with **getting to know each other?** I'll be able to see my mentee's body langue more clearly.	How would in-person mentoring make **scheduling** hard? Arranging around free time. Knowing how to get there.	How would e-mentoring help with **scheduling**? Can take place from wherever one is.	How would e-mentoring make **doing activities where you have to work on a worksheet or sort things** hard? We can't both see it.
How would in-person mentoring make it easy to **explain new ideas?** It makes it easier for my mentee to hear my ideas.	How would in-person mentoring make **feeling comfortable with someone new** hard? They might not feel comfortable talking in person.	How would e-mentoring make it easy to **get help if you need help while you are being a mentor**? My mentee wouldn't be able to see me getting help.	How would e-mentoring make it hard to **explain new ideas?** Having to repeat yourself or speak a little too loud because of connection.

Figure A1. Young adult research team's process for identifying the peer mentoring format. A. YRT members responded to prompts about the feasibility of the mentoring approaches (in-person vs. e-mentoring) and B. "posted" color-coded responses on posters. The YRT reviewed the "posted" responses to identify the most important feasibility considerations.

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