EXPLORING THE EXPERIENCES AND ATTITUDES OF HEALTHCARE PROFESSIONALS CARING FOR PEOPLE WITH INTELLECTUAL DISABILITY

By

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People with intellectual disability experience profound health disparities and care inequities. A systematic review focusing on the implementation of community-based mental health interventions for adults with intellectual disability highlighted a dearth of research. However, disparities exist across every area of health, and are not exclusive to mental health services. Previous researchers identified two major contributing factors to the gap in healthcare (a) provider attitudes toward intellectual disability, and (b) inadequate provider training. Therefore, a transformative convergent parallel mixed methods design was conducted to expand and enhance what is available in the literature with two guiding parts to the study. Part one of the study was designed to understand the attitudes of healthcare professionals toward intellectual disability. Part two was designed to explore the experiences of primary care providers caring for adults with intellectual disability. The research question for part one was, what are the attitudes of healthcare professionals toward intellectual disability, with hypotheses that attitudes will be overall positive and may be different based on participant gender and age. Preliminary analysis of data collected from 81 healthcare professionals to date, confirms that healthcare professionals have relatively positive attitudes toward people with intellectual disability. More data is being collected to determine if differences in attitudes based on age and gender are significant. Part two of the mixed-methods study utilized focus groups to answer the following research question, what are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability? A total of seven focus groups were conducted, across three different clinic locations throughout the United States. Each clinic site hosted a family medicine residency program. There were a total of 46 focus groups participants who consisted of faculty, residents, and clinic staff. Analysis yielded two thematic clusters (a) themes regarding experiences caring for patients with intellectual disability, and (b) themes regarding training needs and recommendations. Focus group data from cluster one, regarding the experiences caring for patients with intellectual disability, yielded six salient themes: (a) patient agency, (b) communication strategies, (c) systemic barriers to care, (d) deficit view of disability, (e) equitable healthcare and (f) communication of intellectual disability. Focus group data regarding the second cluster yielded one training salient theme with five subthemes: (a) guardianship processes and consent for treatment procedures (b) mental health assessment delivery and follow-up, (c) knowledge of community resources, (d) communication barriers, and (e) identifying and communicating a diagnosis of intellectual disability. Participants shared that the training sub thematic areas were largely absent in residency education curricular experiences. Results confirmed that improvements in training are needed that incorporate a contextual understanding of disability and empower providers to move past a deficit-based perspective of disability. This dissertation advances the knowledge of clinical care for adults with intellectual disability and training needs for primary care providers working with this patient population. It also serves to advance the field of medical family therapy by highlighting the important role agency, communion, and promoting equitable healthcare play in improving health outcomes for people with intellectual disability.

EXPLORING THE EXPERIENCES AND ATTITUDES OF HEALTHCARE PROFESSIONALS CARING FOR PEOPLE WITH INTELLECTUAL DISABILITY

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By

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DEDICATION

For G. You have been kind and gracious enough to share your life with me. Your friendship has forever changed who I am and how I see the world. Your wisdom and cleverness bring me so much joy. You are kind, thoughtful, and most of all, always patient with me. Thank you for always saying yes when I ask you to come speak with me so we can teach people how to better support people with disabilities, but mostly thank you for just being you.

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PREFACE

I first discovered my passion for addressing the inequities experienced by people with intellectual disability as a college sophomore enrolled in a course on intellectual and developmental disabilities. I knew at the time that I wanted a master’s degree in marriage and family therapy, and vividly remember asking my professor one day in class if there were marriage and family therapists who worked specifically with people with intellectual disability. She explained that there were none known to her, and in fact that it was quite challenging for people with intellectual disability to find a trained therapist to work with at all. She went on to explain that typical treatment consistent of multiple psychotropic medications and little to no talk therapy. I remember thinking to myself, *I cannot be a part of something that ignores an entire group of people. I’m just going to have to figure out how to be a good therapist for people with intellectual disability.*

The next year I started working on my first research project that included participants with intellectual disability as participants. Due to the nature of the project, I was able to see firsthand just how powerful effective research can be at initiating positive change. Good data can shape policy from local to federal levels. I was hooked immediately. By the time I was in my second semester of my junior year in college, I knew I wanted to not only pursue a master’s degree in marriage and family therapy but would want to pursue my doctorate as well. This decision was fueled by my passion to leverage the power of effective research to combat inequities and improve the lives of people with disabilities.

While engaged in my master’s studies to become a marriage and family therapist, I realized that I wanted to intervene on a systemic level rather than mainly at the private practice and agency levels. The idea of writing and shaping policy to improve the care and quality of life for people with disability seemed more in line with my purpose. Becoming a well-trained researcher would be critical to making this to happen. Consequently, pursuing a doctorate in medical family therapy, and learning how to build a research agenda that supports and endorses policies for change has been affirming and confirming of my chosen career path.

Through the literature review process of this dissertation, I identified research that supports and endorses the need for change, confirms my beliefs about why inequities continue to occur, and alerts me to important gaps that need to be filled. This dissertation has highlighted how people with intellectual disability are not receiving adequate, not to mention equitable, healthcare across the board. The original study conducted as a part of the dissertation points to how healthcare providers continue to not receive the training they need to effectively meet the support needs of their patients with intellectual disability. While I fully recognize this dissertation is not even the tip of the iceberg for the systemic and relational research needed to fully address these gaps, my hope is that the data produced from it elevates the voices of patients and supporters and prompts those in positions of power to make the changes that are long overdue for this understudied and patient population.

CHAPTER 1: AN INTRODUCTION TO HEALTHCARE FOR PATIENTS WITH INTELLECTUAL DISABILITY

People with intellectual disability comprise an estimated 1% of the U.S. population (American Psychiatric Association, 2013). Intellectual disability is defined by significant impairments in both cognitive functioning and adaptive behaviors present before the age of 22 (American Psychiatric Association, 2013; Schalock et al., 2021). Impairment in cognitive functioning is primarily measured by Intelligence Quotient (IQ) assessments, with a cut off score of 70 (i.e., two standard deviations below the population average). However, impairments in adaptive behaviors can be multivarious with impacts to conceptual (e.g., language, reading, writing), social (e.g., interpersonal skills, self-esteem, social problem solving), and/or practical behaviors (e.g., use of money understanding of health and safety) (American Psychiatric Association, 2013; Schalock et al., 2021). As a result, people with intellectual disability may have a wide range of support needs. These support needs may shift over time as people learn and gain new skills or when experiencing a shift in natural supports (e.g., aging primary caregivers). The primary care system is poised to identify and respond to these needs; however, the system is lagging in preparing the healthcare workforce to function in this capacity (Sahin & Akyol, 2010; Tervo & Palmer, 2004).

In their most recent report on the state of health care for people with intellectual disability, the U.S. Surgeon General stated, “Compared with other populations, adults, adolescents, and children with [intellectual disability] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care.” (DHSS, 2002, p. 5).

Researchers supporting the Surgeon General's claim noted that people with intellectual disability experience health inequities that lead to higher mortality rates, lower life expectancies, and higher rates of complex medical diagnoses (Bittles et al., 2002; McCarron et al., 2015). To better understand the profound health disparities and inequities experienced by this population, the United States and other countries around the globe have developed several research and policy initiatives. The approach to these initiatives varies greatly, with some countries (e.g., United Kingdom, Australia, Canada) adopting global agendas set forth by the United Nations (e.g., Convention on Rights of Persons with Disabilities; CRPD, 2006); whereas other countries including the United States, have chosen to adopt and promote a national research and policy agenda (e.g., DHHS, 2002; DHSS, 2005). Regardless of the approach taken (i.e., global versus national), the current state of healthcare world-wide for people with intellectual disability is insufficient.

This chapter will (a) highlight the factors contributing to the current state of health inequities experienced by patients with intellectual disability in the United States, (b) introduce a theoretical foundation for better understanding those factors and how they can be effectively addressed, (c) provide an explanation regarding the role of medical family therapists in addressing these factors and promoting equitable healthcare, (d) describe a mixed-method dissertation design aimed at addressing one of the key factors related to health inequities, and (e) provide preliminary findings from the quantitative data collected to date.

Services and Supports: From Segregation to Inclusion

Throughout history, society has struggled with how to meet the support needs of people with intellectual disability and their families (Brown et al., 2017). From the late 1800s until the 1960's, institution-based care was the primary source of supports and services for people with intellectual disability in the United States. Institutionalization focused on providing segregated services, wherein individuals would live in and receive care from a communal setting for the duration of their lives. While these segregated settings were originally developed to provide state of the art specialized supports and services, over time they became riddled with instances of abuse and neglect (Wehmeyer et al., 2000). As a result of this abuse and neglect, in the 1960's parents across the United States led a movement for the closure of institutions, by filing class action lawsuits against their local state-run institutions. These advocacy efforts resulted in states shifting from institution-based to community-based service systems. This movement is now widely recognized as the deinstitutionalization movement (Hewitt et al., 2013). The goal of the deinstitutionalization movement was for people not to just physically live in their communities, but to experience inclusion by living, learning, working, and playing alongside other community residents. Despite the vast majority of people with intellectual disability in the United States now living in community settings, people with intellectual disability continue to experience segregation and a lack of overall inclusion, including but not limited to, inclusion in healthcare.

Barriers to Inclusive Healthcare

In an effort to achieve this goal of social inclusion, the field of intellectual and developmental disabilities has devoted significant resources toward supporting the inclusion of people with intellectual disability through the development of community-based supports and services (AAIDD, 2016). Despite these efforts, people with intellectual disability continue to experience a lack of inclusion (e.g., Krahn et al., 2006; Ouellette-Kuntz et al., 2005). This lack of inclusion is evident when considering healthcare inequities. As a result, researchers within the field of intellectual and developmental disabilities have identified specific factors that contribute to these disparities in hopes of developing more effective and equitable interventions and programs. Ouellette-Kuntz et al. (2005) provided an overview of these disparity factors which can be conceptualized into four broad categories, (a) patient-specific factors, (b) service delivery barriers, (c) policy related barriers, and (d) provider specific barriers.

Patient specific barriers are those barriers which are specific to a given individual with intellectual disability (Ouellette-Kuntz et al., 2005). These barriers may include factors that are related to the individuals' intellectual disability diagnosis (e.g., challenges with communication and health literacy), other related health diagnoses (e.g., seizure disorders), or the resources available to that individual (e.g., transportation to and from healthcare appointments). Service delivery barriers are those factors which are innately imbedded into the healthcare service delivery systems. For example, research has identified that effective patient-provider encounters may require more time for patients with intellectual disability

(Lennox et al., 1997). Given the billing-based time restrictions placed on most service delivery systems, providers may simply not have enough time to adequately meet patients with intellectual disability's healthcare needs (Lennox et al., 1997).

Given the nature of the deinstitutionalization movement (i.e., being brought about at the result of lawsuits filed by parents and advocates), absent or ineffective policies have obstructed many states and communities from developing an effective community-based service system. Laws such as the Americans with Disabilities Act (ADA; 1990) were written to ensure that people with intellectual disability would have more of a physical presence within community-based healthcare services but the federal government and states failed to develop policies that led to inclusive services. As a result, U.S. researchers and healthcare service systems have relied heavily on the *2002 Closing the Gap: A National Blueprint to Improving the Health of People with Mental Retardation* (U.S. Department of Health and Human Services [HHS], 2002), *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* (U.S. Department of Health and Human Services, 2005), and *The Future of Disability in America* (Institute of Medicine, 2007) for developing effective community-based healthcare services. As outlined in the second chapter of this dissertation, research within the context of community-based mental health services appears to indicate that these research and policy agendas have not been sufficient in igniting the development of community-based mental health services for people with intellectual disability. As evidence by the extremely limited research published on the implementation of community-based mental health interventions, both within the United States and abroad.

Policy recommendations regarding the training of primary care providers that utilizes a contextual (Shalock et al., 2020) framework of disability can be found in chapters three and six if this dissertation.

Lastly, two influential provider-specific barriers have contributed to inequities in care (Ouellette-Kuntz et al., 2005). One is inadequate training around the specific health care needs of people with intellectual disability. Healthcare professionals, parents, patients with intellectual disability (Sahin & Akyol, 2010; Tervo & Palmer, 2004), and even independent researchers (Trollor et al., 2016) all recognize that healthcare professionals lack the adequate training needed to effectively support the needs of patients with intellectual disability. This is particularly alarming when considering there are currently no requirements for U.S. medical schools around training providers in working with patients with intellectual disability (Liaison Committee on Medical Education, 2015). The second provider-specific factor is provider attitudes toward intellectual disability (Haslam & Miller, 1992; Ouellette-Kuntz et al., 2003, Rees et al., 1991). Specifically, research indicates that providers' negative attitudes toward people with intellectual disability acts as a barrier to equitable care (Ouellette-Kuntz et al., 2003). This dissertation utilizes a tri-pronged framework to map out the relationship between attitudes of healthcare providers and inclusive healthcare.

Theoretical Underpinning

This dissertation is designed to explore the attitudes and experiences of healthcare professionals to better understand the provider-specific factors that serve as barriers to equitable care for patients with intellectual disability. The proposed dissertation is grounded in (a) Simplican and colleagues' (2015) model for social inclusion, (b) McGuire's (1985) conceptualization of attitudes, and (c) Schalock and colleagues' (2020) multidimensional model of context. Simplican et al. (2015) argued that true social inclusion is the result of community participation and interpersonal relationships. They purported that simply being physically present in one's community does not result in community inclusion. This model provides the basis for the belief that true inclusive community-based supports and services are those which promote interpersonal relationships (e.g., positive relationships between patients and providers) along with physical access to community spaces and services.

Given the research identifying the role of provider attitudes toward intellectual disability in promoting or inhibiting inclusive healthcare (Haslam & Miller, 1992; Ouellette-Kuntz et al., 2003, Rees et al., 1991), efforts aimed at promoting inclusive healthcare should examine the attitudes of healthcare professionals toward intellectual disability. McGuire's conceptualization of attitudes argued that attitudes are portrayed, shaped, informed, and changed by one's thoughts (i.e., cognitions), feelings (i.e., affect), and behaviors (1985). Additionally, attitudes may be developed as a response to a stimulus that is affective, behavioral, and/or cognitive in nature. This conceptualization of attitudes serves as the basis for the understanding the impact of attitudes in the current study.

The multidimensional model of context purported that disability can be best understood as the interaction between an individual and their context (rather than simply in inherent medical diagnosis; Schalock et al., 2020). This understanding of disability does not ignore a person's diagnosis of intellectual disability, but instead understands the diagnosis as just one part of the person’s lived experience. Furthermore, the multidimensional model of context argues that there are multiple layers to a person’s lived experience, and that understanding that person’s support needs can best be understood by exploring the layers of context that person exists within, rather than focusing exclusively on the person (see chapter 3 for a full description of the model).

These three frameworks come together to serve as the underpinning for the current dissertation. Specifically, the understanding that the support needs of people with intellectual disability are best understood when accounting for context (Schalock et al., 2020) and within the healthcare context, inclusion/access (as defined by Simplican et al., 2015) is shaped by the attitudes of healthcare providers (McGuire, 1985). This dissertation is designed to explore how the context (i.e., personal experiences, professional experiences, and training) of healthcare professionals impacts their attitudes toward intellectual disability, and the care they provide to patients with intellectual disability. Its overall aim is to promote inclusive healthcare by gaining a greater understanding of the identified provider-specific factors (i.e., attitudes and professional training) that currently serve as barriers to inclusive healthcare for patients with intellectual disability.

Role of the Medical Family Therapist

The overarching goal of this dissertation is to promote inclusive healthcare for patients with intellectual disability. It also aligns with Lewis and colleagues’ (2014) call for medical family therapists (MedFTs) to advance health equity through research. MedFT’s can advance this understudied area and promote health equity through direct patient care, promoting diversity in the healthcare workforce, conducting research that honors and promotes people' experiences who have been suppressed, and through the development and implementation of interventions that directly intervene with identified barriers for equitable health care (Hodgson et al., 2014).

This dissertation also aims to advance inclusive healthcare for patients with intellectual disability by aligning with the field of MedFT's primary goals of promoting patient agency and communion (McDaniel et al., 1992; McDaniel et al., 2014). MedFT's promote agency and communion by amplifying individuals' voices who historically have not been honored in healthcare (e.g., patients with intellectual disability), allowing for the development of strong communities of support. Lastly, the current study endorses the field's commitment to diversity evidenced in the American Association for Marriage and Family Therapy's (AAMFT; 2018) *Competencies for Family Therapists Working in Healthcare Settings*. Diversity is the sixth domain of competencies and states that MFT's will promote diversity, equity, and inclusion through their clinical work (including direct patient care, training, and supervision), policy engagement, and scholarship (AAMFT, 2018). The main objective of this dissertation was to apply these concepts and competencies toward the promotion of diversity, equity, and inclusion in healthcare for people with intellectual disability, and provide policy and training recommendations based on the research done that work to reduce health inequities and raise consciousness for this understudied and undertreated patient population.

Purpose

This dissertation was designed to identify ways to advance the care of patients with intellectual disability and understand the gaps in healthcare provider training that may be contributing to current inequities. To do this, researchers utilized a transformative convergent parallel mixed methods design (Morgan, 2017) and collected data in two parts. Part one involved administration of the Attitudes Toward Intellectual Disability questionnaire (ATTID; Morin et al., 2013). Previous studies utilized the ATTID to establish a baseline understanding of a specific population's (e.g., healthcare professionals) attitudes toward intellectual disability (Morin et al., 2018), as well as track changes in attitudes pre and post interventions (Sullivan & Mendoca, 2017). Currently, there is no known baseline to establish an understanding of the attitudes of healthcare professionals toward intellectual disability utilizing the ATTID (Morin et al., 2013) in the United States. Part two utilized focus-groups (Kreuger & Casey, 2015) to qualitatively explore the detailed experiences of primary care providers caring for patients with intellectual disability. To make recommendations for training advancements, it is important to collect data on the attitudes, experiences, and knowledge of those currently practicing. The following research questions guided the original research conducted for this dissertation:

a) What are the attitudes of healthcare professionals toward intellectual disability?
b) What are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability?

Due to an insufficient number of participants between group differences, or differences based on demographic hypotheses (see Chapter 4 for hypotheses and related literature) cannot be determined at the time of dissertation submission. Part one's quantitative data will be provided solely as descriptive data (see Appendix A). Part one's data collection will continue, as permitted by IRB approval, and between group comparison analysis will be conducted once the desired sample size of 768 is achieved. As of April 2022, a total of 81 participants completed the ATTID (Morin et al., 2013). The total sample, as well as each of the three clinic location subsamples, reported positive global attitudes, as well as positive attitudes for each of the five subscales. The sensibility/tenderness subscale showed the most negative attitudes across all participant groups (after being reverse coded), and the discomfort subscale showed the most positive attitudes across all participant groups. These findings are in line with data reporting the attitudes of Canadian healthcare professionals (Morin et al., 2018). Findings indicate that providers may feel pity for people with intellectual disability based on their assumptions regarding the quality of life for people with intellectual disability, but likely do not feel fear or discomfort when interacting with people with intellectual disability. As a result, preliminary findings indicate that healthcare provider trainings may benefit from focusing providing healthcare professionals with a fuller understanding of the ways in which people with intellectual disability can, and often do, live meaningful purposeful lives.

Part two of the mixed method design, included qualitative data collected via focus groups. Data was analyzed using Colaizzi's (1978) seven-step phenomenological analysis and the results are reported on in chapters five and six of this dissertation. Part two's findings, along with what will continue to be collected for part one, will help provide a better understanding of the attitudes and experiences of healthcare professionals caring for people with intellectual disability. This understanding can then serve to inform the future development and implementation of educational interventions aimed at providing healthcare professionals with the knowledge and experiences needed to adequately meet the needs of patients with intellectual disability.

As previously stated, this dissertation is a response to Lewis and colleagues' (2014) call for MedFT's to advance health equity through research. The systematic review and original study conducted advance the intellectual disability and MedFT bodies of literature. They add to the understanding and study of intellectual disability and help identify areas to strengthen in the curriculum and preparation of primary care providers who provide the most continuous care for people with intellectual disability across their lifespan. Furthermore, it was designed to promote health equity specifically through conducting research that aims to better understand and address the barriers identified for patients with intellectual disability.

Summary

As outlined in this chapter, people with intellectual disability continue to experience profound health disparities across all areas of health. Research has identified several different hypotheses around what may cause and/or perpetuate these disparities such as the impacts of current policy (see Chapter 3), healthcare professional training practices (Trollor et al., 2016), and attitudes of healthcare professionals toward intellectual disability (Haslam & Miller, 1992; Ouellette-Kuntz et al., 2003, Rees et al., 1991). The current dissertation examined multiple possible contributors to the health disparities experienced by people with intellectual disability. Six chapters form this dissertation: (a) an introduction to intellectual disability and current health disparities experienced by people with intellectual disability, (b) a systematic review examining the impacts of policy on mental health care for people with intellectual disability, (c) a critical literature review detailing possible factors contributing to health disparities of people with intellectual disability, (d) the methodology for the completed dissertation study that examined the attitudes and experiences of healthcare professionals in caring for patients with intellectual disability, (e) results from the completed dissertation study, and (f) recommendations for training primary care providers to effectively and equitably care for patients with intellectual disability.

The first chapter has provided an introduction to the health disparities and inequities experienced by people with intellectual disability and highlighted the barriers to addressing these disparities and inequities. The introduction also described the role of the MedFT in addressing these disparities and inequities through research and practice. This chapter then introduced the current dissertation mixed-methods study, as well as briefly described the theoretical foundation from which the dissertation design was developed. Finally, the introduction has provided preliminary findings for the quantitative data collected to date.

The second chapter is a systematic review of studies examining community-based mental health interventions for adults with intellectual disability. The aims of this review were to: (a) synthesize the available literature around community-based mental health interventions for people with intellectual disability and mental health support needs both within and outside of the United States, and (b) situate those findings within the context of current U.S. policy in order to provide policy recommendations that promote the equitable community-based mental health services. A literature search using the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA; Moher et al., 2009) guidelines and Cooper's (2010) approach to research synthesis was conducted via PsycINFO, Scopus, Psychological and Behavioral Sciences, and Social Sciences, yielding a total of 4,821 articles. Final analysis included six articles with interventions conducted within the United States, and 32 articles published outside of the United States that met the selection criteria. Findings revealed that countries outside of the United States (e.g., the United Kingdom) have made markedly more progress in the development and implementation of mental health interventions. One possible explanation for this discrepancy were differences in guiding policies around inclusive healthcare across the globe. As a result, implications include a further examination of and improvement to current policies that better advocate for the development of inclusive community-based mental health services within the United States.

The third chapter provides a review of the critical literature pertaining to understanding the role of attitudes and experiences of healthcare professionals caring for patients with intellectual disability. This review highlights the need for expanding and enhancing research on the attitudes and experiences of healthcare professionals pertaining to people with intellectual disability. Furthermore, this review highlights the potential role that mental models of disability play in current healthcare training and policies of care (i.e., medical and contextual; Schalock et al., 2020) and argues that future research in the area should work to understand the experiences that shape and reinforce the mental models held by healthcare professionals.

The fourth chapter describes the proposed transformative convergent parallel mixed methods design (Morgan, 2017) aimed at exploring the following research questions: (a) What are the attitudes of healthcare professionals toward intellectual disability? and (b) What are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability? Qualitative focus group data were analyzed using Colaizzi's (1978) seven-step phenomenological method, and utilized several credibility strategies (e.g., peer debriefing, member checking). Qualitative data from part two of the two-part design will be presented in chapter five and explained through the medical and contextual models of disability.

The fifth chapter includes the results from part two of the mixed-methods design (focus groups) and provides related implications for research and practice. A total of 48 participants were recruited from three different clinic locations to participate in a total of 7 focus groups. Participants were faculty, residents, and clinic staff from the three clinic locations, and focus groups were scheduled based on participant role (i.e., residents were only in focus groups with other residents, and faculty were only in focus groups with other faculty). Focus group data were analyzed using Colaizzi's (1978) seven-step phenomenological method and resulted in 6 salient themes and 27 subthemes. The six salient themes included: (a) Patient agency, (b) Communication strategies, (c) Systemic barriers to care, (d) Deficit view of disability, (e) Equitable healthcare and (f) Communication of intellectual disability. A word cloud was also developed, via WordArt.com, to present data collected regarding participants understanding of the term intellectual disability. Words used most often by participants to describe intellectual disability were “delayed,” “average,” and “normal” respectively. Finally, an exhaustive description was developed to provide a succinct description of the findings. Results highlight that participant view disability from a deficit (e.g., medical) model, recommendations are provided regarding the training of healthcare professionals to adopt a contextual understanding of disability.

Finally, chapter six consists of a brief research report which outlines the focus group data specific pertaining to the training needs and experiences of group participants. Analysis yielded five themes specifically pertaining to training needs: (a) guardianship process and consent for treatment procedures, (b) assessment delivery and follow-up, (c) knowledge of community resources, (d) communication barriers, and (e) identifying and communicating a diagnosis of intellectual disability. Recommendations for changes and updates to medical education and residency curriculum are provided.

Conclusion

The purpose of this dissertation was to explore the attitudes of healthcare professionals toward intellectual disability and the experiences of primary care providers caring for patients with intellectual disability. This data will enable researchers to meet the overall goal of better understanding the barriers that contribute to the current health disparities experienced by people with intellectual disability. The results of the proposed dissertation can then be utilized to develop effective training and education interventions for primary care providers around the treatment of patients with intellectual disability and advance the agenda of the field of medical family therapy through the promotion of equitable healthcare.

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CHAPTER 2: THERAPEUTIC INTERVENTIONS FOR INDIVIDUALS WITH INTELLECTUAL DISABILITY: A SYSTEMATIC REVIEW[1]

The overall health and well-being of adults with intellectual disability has largely been ignored throughout history [1, 2]. Healthcare professionals often focus solely on the person's' disability diagnoses, ignoring other important facets of health. This process has been described as diagnostic overshadowing and is particularly common among people with intellectual disability [3]. Diagnostic overshadowing for adults with intellectual disability and mental health support needs, combined with the shift beginning in the 1970's, from an institutional to a community-based service system [4], contribute to what Krahn and colleagues [5] identify as a cascade of disparities. This, compounded with a significant decrease in overall services available to people with intellectual disability once they reach adulthood [6], creates a concerning gap in services for adults with intellectual disability and mental health diagnoses.

Despite significant attempts to address this cascade of disparities [7], adults with intellectual disability continue to be 2.5 times more likely to have a mental health diagnosis [8], with the most common diagnosis being depression [9,10]. Depression for people with intellectual disability often results in significant concerns with loneliness as well as negative impacts on physical health [11,12]. People with intellectual disability also remain significantly less likely to receive psychotherapeutic community-based mental health services for these diagnoses (i.e., outpatient services accessed by both people with and without

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[1] The current chapter is under review for publication in a journal that does not accept APA formatting.

intellectual disability) than their peers without intellectual disability [13]. Additionally, estimates show that between 25% and 50% of people with intellectual disability are prescribed psychotropic medication [14, 15], despite findings that approximately one third of those people who are prescribed psychotropic medications have no confirmed mental health diagnosis [14]. These data highlight that people with intellectual disability are vulnerable to being overmedicated with psychotropic medications and under supported by psychotherapeutic community-based mental health services.

In recognition of the profound lack of services and supports, and in acknowledgment of the rights of people with disabilities across the globe, the General Assembly of the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 [16]. This convention's sole purpose is to address global discrimination against people with disabilities across multiple areas, including health care [16]. Specifically, Article 25 of the CRPD advocates for persons with disabilities to have the right to access and benefit from healthcare at the same level afforded to other persons without disabilities [16]. While 94 countries around the globe ratified the CRPD (including the optional protocol) and adopted national strategies aimed at providing equitable healthcare, the United States remains among a handful of countries that have not proceeded with its adoption [17].

Instead, the United States has relied on three major documents over the last 19 years to guide its' initiatives to combat the health disparities experienced by people with intellectual disability: (a) 2002 Closing the Gap: A National Blueprint to Improving the Health of People with Mental Retardation [18], (b) The Surgeon General's Call to Action to

Improve the Health and Wellness of Persons with Disabilities [15], and (c) The Future of Disability in America [20]. Of note, the Surgeon General's Closing the Gap report [18] outlines six overarching goals toward developing evidence-based practices that promote equitable healthcare for people with intellectual disability. The first goal focuses specifically on promoting inclusive, community-based (as opposed to segregated, institutionalized) healthcare supports and services.

The model of social inclusion designed by Simplican and colleagues [21] identified community participation and interpersonal relationships as the two key components of social inclusion. Specifically, they argued that true social inclusion cannot be experienced by people with intellectual disability unless those people: (a) possess interpersonal relationships with people with and without disabilities; and (b) are physically present (i.e., live, work, play, worship, and engage in healthcare) in the same community spaces as people without disabilities. Numerous research studies [22, 23] confirmed how segregated (i.e., non-community based) service systems lead to inequitable care. In contrast, research within the field of disability studies identifies that inclusive support and services benefit both people with and without intellectual disability [24, 25].

Over the last decade, research teams conducted three systematic reviews examining psychotherapeutic mental health interventions for people with intellectual disability [26-28]. Each review included studies in inpatient and community-based settings, within and outside of the U.S. The first review focused on mindfulness interventions [26]; the second on dialectical behavior interventions (DBT) [27]; and the third covered all third wave therapeutic interventions (i.e., acceptance and commitment therapy (ACT), DBT, compassion focused therapy (CFT), mindfulness) [28]. However, given the differences in guiding policy (i.e., the U.S. Surgeon General’s report [19] vs. the ratification of the CRPD [16]), as well as the differences in healthcare service delivery systems across countries, it is vital to separate and review research conducted within the U.S. from studies conducted in other countries.

Therefore, given the significant challenges that people with intellectual disability and mental health concerns face in adulthood, the objective of the current review is to synthesize the available literature around psychotherapeutic community-based mental health interventions for adults with intellectual disability and mental health support needs both within and outside of the U.S. The aim of this review is intended to support the development of evidence-based U.S. policy recommendations aimed at addressing the health disparities among adults with intellectual disability and help providers and policy makers advocate for equitable psychotherapeutic community-based mental health services.

Material and Methods

This research synthesis followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) [29] and Cooper’s [30] guidelines. A search of the literature was conducted on September 21, 2020 and again on September 15, 2021 (to include any additional articles that had been published from the original search date) via the PsycINFO, Scopus, Psychological and Behavioral Sciences, and Social Sciences databases. The following search terms were included: Adult AND, intellectual disability OR mental retardation OR developmental disability OR learning disability OR cognitive disability OR

Autism AND, mental health OR psychiatric disorder OR mental distress OR emotional distress AND, service OR treatment OR psychotherapy. Search terms were limited to articles that were published in English and since 2000. Reference lists of included articles were examined but did not result in additional articles meeting the selection criteria.

Screening and Data Extraction

Articles admitted into the review were screened using the following inclusion criteria: (a) available in English, (b) adult participants (18 years and older), (c) participants with intellectual disability (identified prior to study participation or via reported IQ of 70 or lower), (d) empirical studies using either qualitative or quantitative methodologies), and (e) measurement of outcomes from an outpatient psychotherapeutic community-based mental health service or intervention. Articles were excluded based on the following criteria: (a) non-empirical studies, (b) gray literature, (c) measurement of non-mental health related outcomes (e.g., weight loss, behavior only outcomes), (d) studies examining cost effectiveness of an intervention, that did not include measurements on mental health outcomes, and (e) studies exploring participants' perspectives of mental health services in general, not related to a specific intervention or service.

The majority (80%) of title and abstract reviews were conducted by the first and second authors, with the remaining 20% being reviewed by the third author. If there was uncertainty around an article during the abstract review, the article was maintained for full review. The first two authors then applied the selection criteria to all full-text articles for determination of acceptance. Screening procedures were conducted independently to establish interrater reliability. When article eligibility was unclear, discussions were held between all three authors until 100% agreement was reached. Data collected from the studies included participant sample size and demographics, method by which services were reported on within the article, and description of types of services reported on. Information was entered into Google Forms and then reviewed for consistency.

Outcomes from each of the selected studies were reported using ranges, means, or descriptive data. Consistent with the objective of this scoping review, data were reported for summarization purposes and to synthesize the presence of psychotherapeutic community-based mental health service or interventions. Studies were not assessed based on quality of the study or risk of bias in the study, as this is outside the scope of this review. Data from the studies were then entered in an Excel spreadsheet and separated by U.S-based and non-U.S. based studies to determine final summaries and findings. In order to allow reasonable comparisons between the U.S. and non-U.S. based studies, all non-U.S. based studies used were published in English, were member countries of the Organization for Economic Co-operation and Development (OECD) and were classified as high-income countries. This ensured that countries were comparable in terms of typical access to resources for citizens, similar policy-making processes, and would provide similar information about programming in their study write-ups.

Results

The initial search yielded a total of 5,443 results. After, duplicates were removed, a total of 4,821 underwent the title and abstract screening step. During title and abstract review, 4,608 were eliminated. The remaining 213 articles underwent a full article review to ensure the selection criteria were met. A total of 175 articles were eliminated upon full review : (a) 25 articles only described prevalence rates of mental health needs and/or services, (b) 24 articles did not include participants with a diagnosis of intellectual disability, (c) 16 articles lacked empirical data, (d) 5 articles only included participants under the age of 18, and (e) 104 articles were screened out for other reasons (e.g., non-community-based setting, non-mental health related interventions, emphasis on cost effectiveness of inpatient treatments, psychotropic interventions only, general perceptions of mental health not related to a specific intervention, outcomes measured solely by behavioral changes). A total of 32 studies conducted outside of the United States and 6 conducted within the United States were admitted into the review (see Figure 1 for a flowchart of study selection and analysis.). Studies were explored through use of the following categories: (a) participant demographics, (b) mental health service/intervention description, and (c) assessment methods. Participant demographics are presented in Appendix B (U.S. based studies) and Appendix C (non-U.S. based studies). Intervention descriptions are presented in Appendix D (U.S. based studies) and Appendix E (non-U.S. based studies). Assessments used to study changes in mental health are presented in Appendix F (U.S. based studies) and Appendix G (non-U.S. based studies).

U.S. Participant Demographics

There was a total of 222 participants across all six U.S. studies (see Table 1 for complete demographic information). Sample sizes ranged from 3 [31] to 141 participants

[32]. Five of the six studies [31, 33-36] reported a relatively small sample size ranging from 3 to 40, with only one study reporting over 100 participants [32]. The average number of participants per study, across all six studies, was 37 participants. All but one study [32] reported participants' gender. Across those five studies there were 55 males and 26 females. All but two studies [33, 34] reported participants' racial and/or ethnic identities. Across those four studies, 64.2% of the participants reported as white/Caucasian, 29.6% as African American, 7% as Hispanic, 0.6% as Bi-racial, 0.6% as Japanese American, and 0.6% as Asian/Pacific Islander. One study [32] did not report participants' ages, but noted all participants were adults. Participant ages across the other five studies ranged from 19 to 69. One study did not report the mean age of participants nor were the authors able to calculate it themselves based on the information provided. However, across the other five studies there was a mean age of 37. None of the studies reported on participants' religion, sexual orientation, or transgender status. Across all six studies, participants reported having general intellectual disability, with only one study [33] reporting a small percentage (18%) of participants having co-morbid autism spectrum disorder.

Non-U.S. Participant Demographics

There was a total of 667 participants across the 32 non-US studies (see Table 2 for complete demographic information). The number of participants ranged from single-participant case studies [37-43] to 161 [44]. It should be noted that all studies but one [44] included 80 participants or less. The average number of participants per study, across all 32 studies, after removing single-participant case studies, was 26.4 participants. Three studies

[45-47] did not report the participants' gender; however, all of the participants in one article [47] identified as mothers. There was a total of 299 participants who identified as female and 318 participants who identified as male. It was unclear if any of the studies provided participants the opportunity to identify in any way other than male or female. Only six of the 32 studies reported participants' racial and/or ethnic identities [37, 38, 43, 44, 47, 48]. Of the six studies that did report, the vast majority, 95.2%, of the participants reported as white, 1.2% reported as Aboriginal, and 3.5% reported as other. Four studies [49-52] either did not report participants' age or reported age in a way that did not allow for the calculation of average age of participants. For the remaining 30 studies participants' age ranged from 17-73, with the average age ranging from 27.6 to 42.2 years (M = 36.9). Two studies [46,53] had one participant each who was 17 but all other participants were 18 or older so they were included in the review. None of the studies reported participants' religion, sexual orientation, or transgender status. Across all 32 studies, participants were reported as having general intellectual disability.

U.S. Mental Health Services/Interventions

Of the six U.S. studies, five provided theory specific interventions, with two providing Cognitive Behavioral Therapy (CBT) [35,36] one providing Dialectical Behavioral Therapy (DBT) [33], one providing Eye Movement Desensitization and Reprocessing (EMDR) [34], and one providing Progressive Muscle Relaxation techniques [31]. The sixth study reported a "supportive psychotherapy program" which aimed to increase positive coping skills but was not theory specific. For two studies [32,33] interventions were provided by clinical social workers, while the remaining studies' interventions were conducted by clinical psychologists. Treatment configuration was reported as individual sessions [31,33], group sessions [35,36], or a combination of both group and individual sessions [33]. One study did not provide details on treatment configuration [32]. Most treatments were provided in weekly sessions, with two studies providing sessions up to two [32] and three [33] times per week. The two CBT group treatments [35,36] were predetermined in length (9 and 10 weeks) based on manualized treatment procedures. The DBT treatment [33] utilized a manualized treatment but was adapted based on individual participant support needs. The remaining intervention studies provided treatment based on the participants' needs and treatment outcomes. One retrospective study [32] examined participants' treatment records over a 12-month time frame. See Table 3 for full list of interventions.

Non-U.S. Mental Health Services/Interventions

Of the 32 non-U.S. studies, 11 provided CBT interventions (see Table 4 for full list). Four studies provided Psychodynamic therapy [36,43,53,54]. Three studies provided Behavioral Activation interventions [42,44,55]. Three studies provided EMDR interventions [38,56,57]. Three studies provided Compassion Focused Therapy (CFT) [39,58,59]. Two studies provided Mindfulness interventions [48,50]. Two studies provided social skills groups [47,49]. The remaining studies provided Brief-Solution Focused Therapy (BSFT) [52], Exposure therapy [40], a psychoeducation intervention [60] and relaxation techniques [61]. All non-U.S. studies except for two [37,49] reported interventions being provided by clinical psychologist, clinical social worker, or a therapist. The remaining two studies did not report the training or licensure of the professionals providing the interventions. Treatment configuration was reported as individual for 19 studies, and group for 13 studies. Twenty-two of the studies reported pre-determined lengths of treatment based on study design, while the remaining 10 studies reported length of treatment as based on participant needs (i.e., termination took place when participants' symptoms were well managed). Four of the studies [37,38,49,54] did not report the frequency of intervention treatment. One study [62] reported only one session total. The remaining 27 studies reported weekly interventions occurred.

U.S. Assessment Methods

The two retrospective studies (i.e., studies examined participant intervention outcomes through assessments in place prior to study being conducted) [32, 33] examined agency charts for changes in participants' mental health symptoms and related behaviors. One study did not utilize a validated measure to assess outcomes, and instead utilized an internal (agency specific) rating system to communicate frequency and severity of behavior incidents related to mental health symptoms [33]. The other retrospective study utilized a validated measure that had been incorporated into the agency's assessment procedures prior to the time frame that data were culled from agency documentation [32]. Two of the intervention studies used only measures previously validated for people with intellectual disability to assess changes in mental health symptoms [33, 36]. A third intervention study [31] utilized measures previously validated for people with intellectual disability, and a two-item Likert-scale developed by the study's researchers to assess for participant mental health outcomes. The fourth intervention study [36] utilized a combination of measures that were and were not validated for people with intellectual disability. This was primarily due to a lack of validated measures for trauma and PTSD for use with this population. See Table 5 for a full list of assessments by study.

Non-U.S. Assessment Methods

All 32 non-U.S. studies were intervention-based studies. Four studies utilized only assessments that had been validated for people with intellectual disability [42,49,63,64]. Six utilized assessments that had not previously been established for use with people with intellectual disability [36,38,40,47,60,62]. A total of 13 studies [39,43,44,48,53,55,56,58,59,61,65-67] utilized a combination of assessments that had and had not been previously established for use with people with intellectual disability. Four studies [39,50,52,60] utilized assessments which were developed specifically for the purpose of the study and therefore had not been previously validated for people with or without intellectual disability. Seven studies [45,46,51,54,57,68,69] utilized qualitative interviews with participants as a form of measuring changes in mental health symptoms. Of those seven studies two [43,44] utilized a mixed methods design which included formal assessments and in-depth interviews. See Table 6 for a fill list of assessments by study.

Discussion

The purpose of this review was to provide a synthesis of current research around psychotherapeutic community-based mental health interventions for adults with intellectual disability within the context of current global and U.S. policies. Three previous reviews have been conducted that examine psychotherapeutic interventions for adults with intellectual disability [22-24]. Each of these previous reviews focus on a specific sub-set of psychotherapeutic interventions (i.e., mindfulness, dialectical behavior interventions, third-wave therapeutic interventions). The current review adds to the body of literature by exclusively exploring studies that include mental health outcomes, provide services in a community-based setting, and separating studies based on country of origin (i.e., within the United States or outside of the United States). The current literature search revealed limited research examining the effectiveness of psychotherapeutic community-based mental health services both within and outside of the United States. Specifically, participant demographics across all studies showed that a majority of studies included small samples sizes that were racially/ethnically homogenous (i.e., primarily white/Caucasian). Furthermore, participant gender was exclusively reported as a binary variable (i.e., male, female). Improvements are needed in collecting demographics that acknowledge how the intersectionality of privileged and subjugated identities [70] may influence equitable access to psychotherapeutic community-based mental health services.

Of the five interventions explored in U.S., one previously developed evidence-based intervention (CBT) was implemented in more than one study. In contrast, non-U.S. studies included 13 different interventions, with six interventions being reported in two or more studies. In addition to the deficits within the development of specific interventions, the difference in the amount of research being conducted based on country of origin is noteworthy. For example, the United Kingdom (UK) has produced 21 studies that fit the inclusion criteria for the current review, compared to the four peer-reviewed published studies and two dissertations conducted in the United States. The current findings hold implications for both research and policy.

Research Implications

Despite historical opinion [3,71] research conducted within and outside of the United States suggests people with intellectual disability have mental health support needs and can benefit from psychotherapeutic community-based mental health services. The small amount of current U.S. research in this area, four published articles and two dissertations, exemplifies the lack of evidence-based, psychotherapeutic community-based mental health services for this community within the Unites States. As the current review did not report on the effectiveness of each intervention included, nor explore the strength of intervention and study design for each article included, more research is needed in this area. Specifically, which mental health interventions require modifications (e.g., creating visuals, adjusting language based on participant preferences in communication) to effectively support people with intellectual disability, as well as which interventions are most efficacious. Studies aimed at answering these questions will also require the development of additional validated self-report measures to assess changes in mental health symptoms for people with intellectual disability. Given that current mental health services for people with intellectual disability rely heavily on the use of psychotropic medication [14,73], research is needed to better understand how psychotherapeutic community-based mental health professionals can best collaborate with local medical providers to design patient-centered treatment plans that are inclusive of many different options of evidence-based therapies.

Policy Implications

It has long been acknowledged that data can and should drive policy [73]. In the early 2000s, countries world-wide began to adopt both policies and public health agendas to reduce health disparities for people with intellectual disability [5]. Two decades later, the current review points to a continued imbalance of research efforts and paucity of work done within the Unites States, when contrasted with other comparable countries across the globe. Since 2002, when the U.S. Surgeon General's Closing the Gap report (HHS) [18] was published, four articles and two dissertations have been completed examining psychotherapeutic community-based mental health interventions. This small body of work considered within the context of current data on health disparities and inequities [4,5] seem to indicate that the current public health agenda of the United States is not effectively meeting the mental health needs of people with intellectual disability. Therefore, we feel it is time for the U.S. policy makers to consider the development and implementation of policies, such as ratifying Article 25 of the CRPD [16]. A shift in policy can then lead to the effective designation of resources toward the implementation and evaluation of evidence-based psychotherapeutic community mental health services for people with intellectual disability.

Strengths and Limitations

This is the first review known to the authors to synthesize literature on several different psychotherapy interventions for adults with intellectual disability, rather than focusing on a subset of interventions. This strengthens the current body of literature by providing a broad overview, which allows researchers to better understand the major gaps in the literature. Additionally, this review considers interventions conducted both within and outside of the United States and situates the results in a way that allows researcher to identify helpful comparison gaps in the current literature, providing a clear outline for what specific areas of research need to be addressed in the future.

This review has a few limitations to note. The first limitation is that despite multiple searches, some articles may have been missed due to search engines and terms used. All articles accessed were also only published in English, which may have limited the sample, especially for studies conducted outside of the Unites States. Another limitation is the fact that the authors did not have access to the original data of each study, and so were reliant only on the information that each article chose to publish. A final limitation is the large range of programs and participants described across all studies reviewed. While this review was aimed at summarizing what research is currently being published and not making conclusions regarding types of treatments, it still provides limitations in what conclusions can be drawn.

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Figure 1

PRISMA Flowchart of Study Selection Process

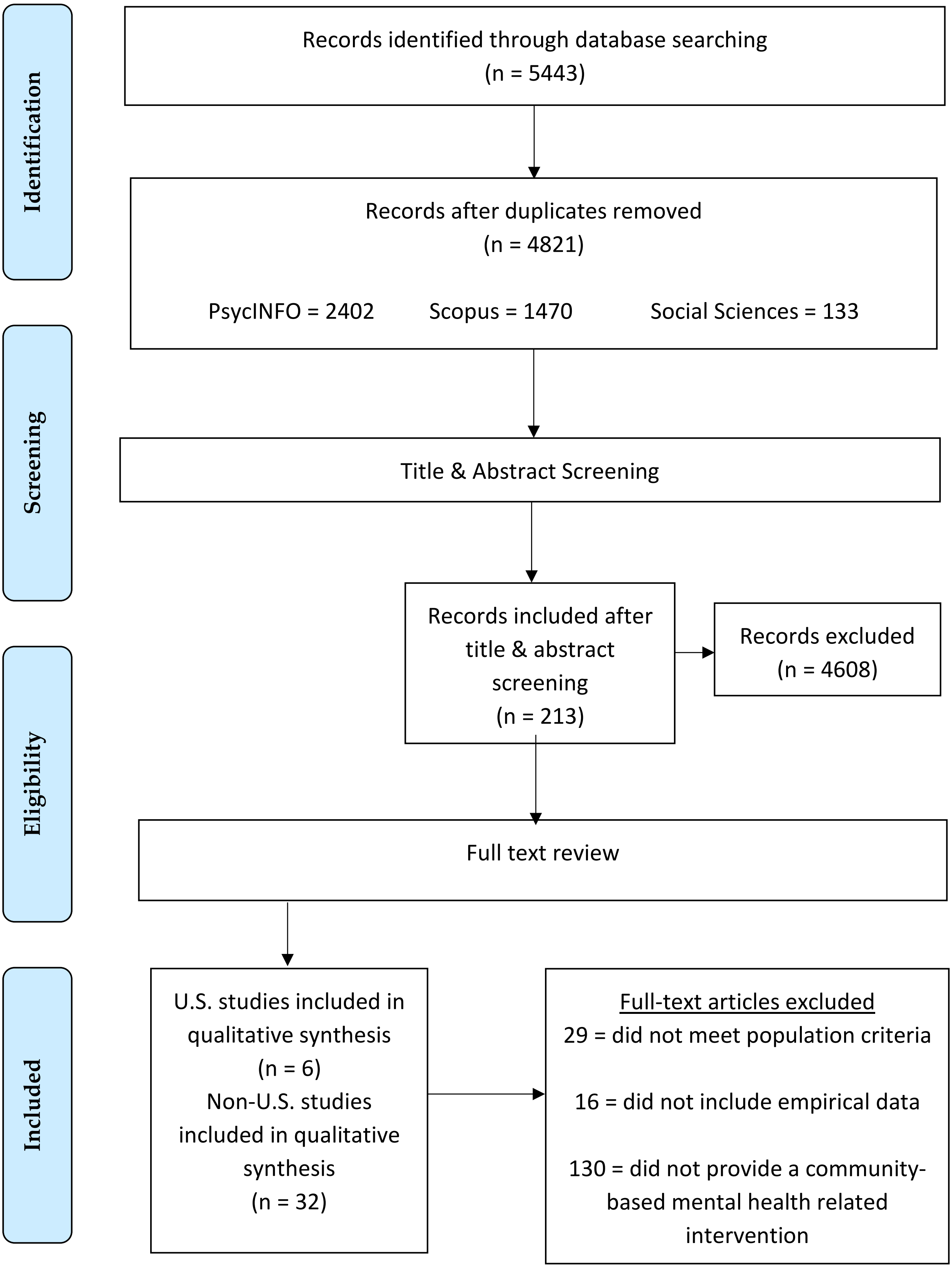

Table 1

U.S. Participant Demographics

Study	Total # Participants	Age		Gender		Race/ Ethnicity
		Range	Mean	Female	Male	
Brown et al., 2013	40	19-63	30.8	5	35	NR
Buhler, 2014	6	37-69	51.7	3	3	NR
Gentile et al., 2014	141	NR	NR	NR	NR	white/ Caucasian - 94 African American - 43 Bi-racial - 1 Hispanic - 1 Japanese-American/ Pacific Islander - 1
Ghafoori et al., 2010	8	19-22	20	6	2	white/ Caucasian - 1 African American - 3 Hispanic - 3 Asian - 1
Hartley, 2015	24	22-54	39.53	11	13	white/Caucasian – 22*
Miller, 2007	3	40-46	43.3	1	2	white/Caucasian - 3

Note. NR = Not Reported; * = the race/ethnicity of two participants was not reported.

Table 2

Non-U.S. Participant Demographics

Study	Total # of Participants	Age		Gender		Race/ Ethnicity
		Range	Mean	Female	Male	
Alim, 2010	1	34	34	0	1	white - 1
Anderson & Kazantzis, 2008	3	19-52	NR	1	2	NR
Barrowcliff & Evans, 2015	1	NR	N/A	1	0	NR
Beail et al., 2005	20	17-48	29.3	3	17	NR
Bouvet & Coulet, 2016	30	NR	40.37	16	14	NR
Bruce et al., 2010	34	21-68	40.5	18	16	NR
Clapton et al., 2018	6	NR	38.5	4	2	NR
Cooney et al., 2018	24	23-69	42	16	8	NR
Cooper & Frearson, 2016	1	NR	N/A	0	1	white - 1
Cowdrey & Walz, 2014	1	39	N/A	1	0	NR
Crowley et al., 2008	8	34-56	44.25	2	6	NR
Fernando & Medlicott, 2009	1	NR	NR	1	0	NR
Green, 2016	1	76	N/A	0	1	NR

Cont.

Study	Total # of Participants	Age		Gender		Race/ Ethnicity
		Range	**Mean**	**Female**	**Male**	
Hardiman et al., 2017	3	31-48	42	2	1	NR
Idusohan-Moizer et al., 2015	15	21-44	30.75	8	7	white British - 15
Jahoda et al., 2015	21	21-63	42.2	9	12	NR
Jahoda et al., 2017	161		40.2	85	76	white - 156 Other - 3
Karatzias et al., 2018	15	NR	42	9	6	NR
Kroese e tal., 2016	10	21-46	33	NR	NR	NR
Lewis et al., 2016	6	20-43	29.3	5	1	NR
MacHahon et al., 2015	11	22-44	NR	3	8	NR
Marwood & Hewitt, 2012	8	17-73	39.25	NR	NR	NR
McCabe et al., 2006	34	22-58	34.05	18	16	NR
McConnell et al., 2008	32	NR	34.1	NR	NR	Aboriginal - 2 Australia – 29 Other - 3

Cont.

Study	Total # of Participants	Age		Gender		Race/ Ethnicity
		Range	**Mean**	**Female**	**Male**	
McGillivary et al., 2008	20	NR	38.4	7	13	NR
McGillivary & Kershaw, 2013	82	18-65	37	35	47	NR
McGillvary & Hershaw, 2015	70	NR	36	28	42	NR
McInnis, 2016	1	28	N/A	0	1	white - 1
Pert et al., 2013	15	26-52	38.8	7	8	NR
Roberts & Kwan, 2018	13	18-55	27.61	7	6	NR
Stoddart et al., 2001	16	NR	NR	10	6	NR
Unwin et al., 2018	3	23-42	35	3	0	NR

Note. NR = Not Reported; N/A = Not Applicable.

Table 3

U.S. Mental Health Services/Interventions

Study	Provider Type	Intervention	Configuration	Frequency of Sessions	Length of Treatment
Brown et al., 2013	Clinical Social Worker	Adapted Dialectical Behavior Therapy	Individual & Group	1-3/week	Participant specific (assessed over 4 years)
Buhler, 2014	Clinical Psychologist	Eye Movement Desensitization and Reprocessing	Individual	1/week	Participant specific
Gentile et al., 2014	Clinical Social Worker	Supportive Psychotherapy Program	Information not provided	1-2/week	Participant specific
Ghafoori et al., 2010	Clinical Psychologist	Cognitive Behavioral Therapy	Group	1/week	Pre-determined 10 weeks
Hartley, 2015	Clinical Psychologist	Cognitive Behavioral Therapy	Group	1/week	Pre-determined 9 weeks
Miller, 2007	Clinical Psychologist	Progressive Muscle Relaxation	Individual	2/week	Participant specific

Table 4

Non-U.S. Mental Health Services/Interventions

Study	Provider Type*	Country	Intervention	Configuration	Frequency of Sessions	Length of Treatment
Alim, 2010	NR	United Kingdom	Psychodynamic/ Milan	Individual	NR	Pre-determined
Anderson & Kazantzis, 2008	NR	New Zealand-Community	Social problem-solving skills	Individual	NR	Pre-determined
Barrowcliff & Evans, 2015	Clinical Psychologist	United Kingdom	Eye Movement Desensitization and Reprocessing	Individual	NR	Participant specific
Beail et al., 2005	Clinical Psychologist	United Kingdom	Psychodynamic	Individual	1/week	Participant specific
Bouvet & Coulet, 2016	clinical psych and undergrad student	France	Relaxation techniques	Group	1/week	Pre-determined
Bruce et al., 2010	Clinical Psychologist	United Kingdom	Cognitive Behavioral Therapy training session	Individual	1 hour total	Pre-determined
Clapton et al., 2018	Clinical Psychologist	United Kingdom	Compassion Focus Therapy	Group	1/week	Pre-determined
Cooney et al., 2018	Clinical Psychologist	Ireland	Computerized Cognitive Behavioral Therapy	Individual	1/week	Pre-determined

Cont.

Study	Provider Type*	Country	Intervention	Configuration	Frequency of Sessions	Length of Treatment
Cooper & Frearson, 2016	Psychologist	United Kingdom	Compassion Focus Therapy	Individual	1/week	Participant specific
Cowdrey & Walz, 2014	Clinical Psychologist	United Kingdom	Exposure Therapy	Individual	1/week	Participant specific
Crowley et al., 2008	Psychologist	United Kingdom	Psychoeducation on Psychosis	Group	1/week	Pre-determined
Fernando & Medlicott, 2009	Clinical Psychology intern	New Zealand	Mindfulness	Individual	1/week	Participant specific
Green, 2016	Psychologist	United Kingdom	Behavior Activation	Individual (with partner present)	1/week	Participant specific
Hardiman et al., 2017	Clinical Psychologist	United Kingdom	Compassion Focus Therapy	Individual	1/week	Pre-determined
Idusohan-Moizer et al., 2015	Clinical Psychologist	United Kingdom	Mindfulness-Based Cognitive Therapy	Group	1/week	Pre-determined
Jahoda et al., 2015	Research psychologist	United Kingdom	Behavioral Activation	Individual	1/week	Pre-determined

Cont.

Study	Provider Type*	Country	Intervention	Configuration	Frequency of Sessions	Length of Treatment
Jahoda et al., 2017	"therapists"	United Kingdom	Behavior Activation- 'BeatIt' and "StepUp'	Individual	1/week	Pre-determined
Karatzias et al., 2018	Psychiatrist, Clinical Psychologist, Social Worker	United Kingdom	Eye Movement Desensitization and Reprocessing	Individual	1/week	Pre-determined
Kroese e tal., 2016	Clinical Psychologist	United Kingdom	TF-CBT	Group	1/week	Pre-determined
Lewis et al., 2016	Psychologist	United Kingdom	Psychotherapy	Individual	NR	Participant specific
MacHahon et al., 2015	Clinical Psychologist	United Kingdom	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
Marwood & Hewitt, 2012	Clinical Psychologists in training	United Kingdom	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
McCabe et al., 2006	Psychologist	Australia	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
McConnell et al., 2008	Psychologist and Social Workers	Australia	Social Group	Group	1/week	Pre-determined

Cont.

Study	Provider Type*	Country	Intervention	Configuration	Frequency of Sessions	Length of Treatment
McGillivary et al., 2008	Psychologist train Disability Staff	Australia	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
McGillivary & Kershaw, 2013	Psychologist train Disability Staff	Australia	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
McGillvary & Hershaw, 2015	Psychologist train Disability Staff	Australia	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
McInnis, 2016	Psychologist	United Kingdom	Psychodynamic/ Malan	Individual	1/week	Participant specific
Pert et al., 2013	Therapists	United Kingdom	Cognitive Behavioral Therapy	Individual	1/week	Participant specific
Roberts & Kwan, 2018	Therapists	Australia	Cognitive Behavioral Therapy	Group	1/week	Pre-determined
Stoddart et al., 2001	Clinical Social Worker	Canada	Brief-solution focused therapy	Individual	1/week	Pre-determined
Unwin et al., 2018	Clinical Psychologist	United Kingdom	Eye Movement Desensitization and Reprocessing	Individual	1/week	Participant specific

Note. NR=Not Reported.

Table 5

U.S. Assessment Methods

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Brown et al., 2013	Retrospective	Behavior data from agency charts	Residential agency staff	Daily during 4 years
Gentile et al., 2014	Retrospective	Problem Severity Scale	Information not provided	Baseline and 12 months out
Buhler, 2014	Intervention	Personality Assessment Inventory	Self-report	Pre & Post intervention phase
		Developmental Behavior Checklist**	Caregiver report	Pre & Post intervention phase
		Children's PTSD Inventory	Self-report	Pre & Post intervention phase
		Impact of Events Scale-Revised	Self-report	Pre & Post intervention phase
		Trauma Symptoms Checklist for Children	Self-report	Weekly during intervention phase
		Brief Symptom Inventory**	Self-report	Weekly during intervention phase
		The Aberrant Behavior** Checklist	Caregiver report	Weekly during intervention phase
		Social Performance Survey Schedule (SPSS)**	Caregiver report	Weekly during intervention phase
Ghafoori et al., 2010	Intervention	Symptom Checklist-90-Revised**	Self-report	Pre & Post intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Hartley, 2015	Intervention	Self-Report Depression Questionnaire**	Self-report	Pre, Post, & 3 month follow up from intervention phase
		Caregiver version of Glasgow Depression Scale - LD**	Caregiver report	Pre, Post, & 3 month follow up of intervention phase
		Scale of Independent Behavior: Revised Problem Behavior Scale**	Caregiver report	Pre, Post, & 3 month follow up of intervention phase
		Social Performance Survey Schedule**	Caregiver report	Pre, Post, & 3 month follow up of intervention phase
Miller, 2007	Intervention	Emotion Problem Scale: Self-Report Inventory- Anxiety Subscale**	Self-report	Weekly during intervention phase and at 1 month follow up
		Emotion Problem Scale: Behavior Rating Scales- Anxiety Subscale**	Case manager	Weekly during intervention phase and at 1 month follow up
		Anxiety and Relaxation Inventory*	Self-report	Weekly during intervention phase

Note. * = this assessment was designed for this study and has not yet been validated outside of the study; ** = an assessment that has been previously validated for people with intellectual disability

Table 6

Non-U.S. Assessment Methods

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Alim, 2010	Intervention	Brief Symptom Inventory	NR	Pre & Post intervention phase
		Inventory of Interpersonal Problems	Self-Report	Pre & Post intervention phase
		Rosenberg Self-Esteem Scale	Self-Report	Pre & Post intervention phase
Anderson & Kazantzis, 2009	Intervention	Adapted Zung Anxiety Inventory**	Self-Report	Pre, Post, and 4 week follow up from intervention phase
		Adapted Zung Depression Scale**	Self-Report	Pre, Post, and 4 week follow up from intervention phase
		Adapted Rosenberg Self-Esteem Scale**	Self-Report	Pre, Post, and 4 week follow up from intervention phase
		Social Problem-Solving Skills Measure	Self-Report	Pre, Post, and 4 week follow up from intervention phase
Barrowcliff & Evans, 2015	Intervention	Revised Child Impact of Events Scale	Self-Report and Clinician report	Pre & Post intervention phase
Beail et al., 2005	Intervention	Symptom Checklist 90-Revised**	Self-report (with support)	Pre, Post, and 3 month follow up from intervention phase
		Inventory of Interpersonal Problems	Self-report (with support)	Pre, Post, and 3 month follow up from intervention phase
		Rosenberg Self-Esteem Scale**	Self-Report	Pre, Post, and 3 month follow up from intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Bouvet & Coulet,	Intervention	Rosenberg Self-Esteem Scale (French Version)**	Self-Report	Pre & Post intervention phase
2016		EmotionRegulation Questionnaire (French Version)	Self-Report	Pre & Post intervention phase
		STAI-Y of Spielberger (French Version)**	Self-Report	Pre & Post intervention phase
Bruce et al., 2010	Intervention	Thought-Feeling-Behavior task*	Self-report	Pre & 1 week post intervention phase
		Thought to Feeling task*	Self-report	Pre & 1 week post intervention phase
Clapton et al., 2018	Intervention	Self-Compassion Scale- Short Form*	Self-report	Pre & Post intervention phase
		Psychological Therapy Outcome Scale for Intellectual Disabilities**	Self-report	Pre & Post intervention phase
		Adapted Social Comparison Scale**	Self-report	Pre & Post intervention phase
Cooney et al., 2018	Intervention	Qualitative Interviews	Self-report	Post intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Cooper & Frearson, 2016	Intervention	Clinical Outcomes in Routine Evaluation- Learning Disability**	Self-Report	Pre & Post intervention phase
		Forms of Self-Criticizing/Attacking and Self-Reassuring Scale	Self-report (with support)	Pre & Post intervention phase
		Mood Monitoring*	Self-report	Weekly during intervention phase
Cowdrey & Walz, 2014	Intervention	Spider Phobia Questionnaire*	Self-report (with support)	Pre intervention, and weekly during intervention phase
Crowley et al., 2008	Intervention	Crown Self Esteem Scale	Self-report (with support)	Pre & Post intervention phase
		What do you know about psychosis' questionnaire*	Self-report (with support)	Pre & Post intervention phase
Fernando & Medlicott, 2009	Intervention	Mood Monitoring*	Self-Report	Pre & daily during intervention phase
		Intrusive thought monitoring*	Self-Report	Pre & daily during intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Green, 2016	Intervention	Glasgow Depression Scale - LD**	Self-Report	Pre & Post intervention phase
		Glasgow Anxiety Scale- ID **	Self-Report	Pre & Post intervention phase
Hardiman et al., 2017	Intervention	Self-Compassion Scale	Self-Report	Pre & Post intervention phase
		Glasgow Anxiety Scale- ID**	Self-Report	Pre & Post intervention phase
Idusohan-Moizer et al., 2015	Intervention	Hospital Anxiety and Depression Scale **	Self-Report	Pre, Post, 6-week follow-up from intervention phase
		The Compassion Scale	Self-Report	Pre, Post, 6-week follow-up from intervention phase
Jahoda et al., 2015	Intervention	Glasgow Depression Scale - LD **	Self-Report	Pre, Post, & 3-month follow-up from intervention phase
		Intellectual Disabilities Depression Scale **	Identified Caregiver	Pre, Post, & 3-month follow-up from intervention phase
		Index of Community Involvement	Self-report (with support)	Pre, Post, & 3-month follow-up from intervention phase
		Index of Participation in Domestic Life	Self-report (with support)	Pre, Post, & 3-month follow-up from intervention phase
		Health of the Nation Outcome scale- LD Version **	Identified Caregiver	Pre, Post, & 3-month follow-up from intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Jahoda et al., 2017	Intervention	Glasgow Depression Scale - LD **	Self-Report	Pre, 4-months post, & 12-months post intervention phase
		Intellectual Disabilities Depression Scale **	Identified Caregiver	Pre, 4-months post, & 12-months post intervention phase
		EuroQol 5 Dimensions Questionnaire	Self-Report	Pre, 4-months post, & 12-months post intervention phase
		Index of Community Involvement	Self-report (with support)	Pre, 4-months post, & 12-months post intervention phase
		Index of Participation in Domestic Life	Self-report (with support)	Pre, 4-months post, & 12-months post intervention phase
		Social Support Questionnaire	NR	Post intervention
		Adaptive Behavior Scale **	NR	Post intervention
Karatzias et al., 2018	Intervention	Post-Traumatic Stress Disorder Checklist	Self-Report	Pre, 1-week post, & 3-month post intervention phase
		Glasgow Anxiety Scale - LD **	Self-report	Pre, 1-week post, & 3-month post intervention phase
		Glasgow Depression Scale - LD **	Self-report	Pre, 1-week post, & 3-month post intervention phase
		Clinical Outcomes in Routine Evaluation- LD**	Self-Report	Pre, 1-week post, & 3-month post intervention phase
Kroese et al., 2016	Intervention	Impact of Events Scale- ID**	Self-Report	Pre & Post intervention phase
		Qualitative Interviews	Self-Report	Post intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Lewis et al., 2016	Retrospective	Qualitative Interviews	Self-Report	Post intervention phase
MacHahon et al., 2015	Intervention	Qualitative Interviews	Self-Report	Post intervention phase
Marwood & Hewitt, 2012	Intervention	Qualitative Interviews	Self-Report	Post intervention phase
		Quality of Life Scale	Self-report (with support)	Pre & Post intervention phase
		Glasgow Anxiety Scale**	Self-report (with support)	Pre & Post intervention phase
		Health of the Nation Outcome scale- LD Version**	Self-report (with support)	Pre & Post intervention phase
McCabe et al., 2006	Intervention	Beck Depression Inventory	Self-Report	Pre, Post, & 3-month follow-up from intervention phase
		Social Comparison Scale**	Self-Report	Pre, Post, & 3-month follow-up from intervention phase
		Rosenberg Self-Esteem Scale**	Self-Report	Pre, Post, & 3-month follow-up from intervention phase
		Automatic Thoughts Questionnaire - Revised **	Self-Report	Pre, Post, & 3-month follow-up from intervention phase
McConnell et al., 2008	Intervention	Depression, Anxiety, and Stress Scales	Self-Report	Pre & Post intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
McGillivary et al., 2008	Intervention	Beck Depression Inventory	Self-Report	Pre & Post intervention phase
		Automatic Thoughts Questionnaire - Revised **	Self-Report	Pre & Post intervention phase
		Social Comparison Scale	Self-Report	Pre & Post intervention phase
McGillivary & Kershaw, 2013	Intervention	Beck Depression Inventory	Self-Report	Pre, Post, & 8-month follow up from intervention phase
		Automatic Thoughts Questionnaire - Revised **	Self-Report	Pre, Post, & 8-month follow up from intervention phase
McGillvary & Hershaw, 2015	Intervention	Beck Depression Inventory	Self-Report	Pre, Post, & 6-month follow up from intervention phase
		Automatic Thoughts Questionnaire - Revised **	Self-Report	Pre, Post, & 6-month follow up from intervention phase
McInnis, 2016	Intervention	Brief Symptom Inventory	Self-report (with support)	Pre, 11-months into, 23-months into, & Post intervention phase
		Manchester Attachment Scale - Third Part Observational Measure **	Identified Caregiver	Post intervention phase
Pert et al., 2013	Intervention	Qualitative Interviews	Self-Report	After 4th and 9th session during intervention phase
Roberts & Kwan, 2018	Intervention	Glasgow Anxiety Scale - ID**	Self-Report	Pre & Post intervention phase
		Thought-Feeling-Behavior task	Self-Report	Pre & Post intervention phase
		Thought-to-Feeling task	Self-Report	Pre & Post intervention phase

Cont.

Study	Study Design	Mental Health Outcome Assessments	Assessment Informant	Data Collection Timing
Stoddart et al., 2001	Intervention	Independent clinician rating**** Service Evaluation Questionnaire	Clinician/researcher Self-report	Post intervention phase 6-months Post intervention phase
Unwin et al., 2018	Intervention	Qualitative Interviews	Self-Report	Post intervention phase

Note. * = this assessment was designed for this study and has not yet been validated outside of the study, ** = an assessment that has been previously validated for people with intellectual disability

CHAPTER 3: LITERATURE REVIEW

Over the last 20 years, the field of intellectual and developmental disabilities has placed significant effort toward identifying the unique health challenges experienced by people with intellectual disability. Synthesis of this research highlights health disparities (Krahn & Fox, 2012) and health inequities (Mizen et al., 2012) from the clinical service to policy levels. Health disparities are defined by Ouellette-Kuntz et al. (2005) as “population specific differences in health indicators.” (p. S9). Documented health disparities experienced by people with intellectual disability include, but are not limited to, (a) shorter life expectancy (Bittles et al., 2002), (b) increased mortality rates (Bittles et al., 2002), and (c) higher rates of complex medical diagnoses such as seizure disorders (Hollander et al., 2005). Health inequities are defined as, “the presence of disparities in health and in its key demographic, social, economic, and political determinants that are systematically associated with social advantage/disadvantage.” (Ouellette-Kuntz et al., 2005, p. S9). Examples of documented health inequities include: (a) poor healthcare provider education (Weise & Trollor, 2017; WHO, 2011), and (b) healthcare providers’ negative attitudes toward intellectual disability (Sahin & Akyol, 2010; Tervo & Palmer, 2004). Ultimately, Ouellette-Kuntz and colleagues (2005) argued health disparities cannot be fully eliminated until health inequities are addressed adequately. To effectively address health inequities, governments across the globe developed policy initiatives supporting the effective training and education of healthcare providers in caring for patients with intellectual disability.

In 2006, the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and 25th amendment, pertaining specifically to the right to equitable healthcare, were developed to establish a global standard for the basic rights for people with disabilities. To date, 94 countries ratified the full CRPD. The United Kingdom (UK) and Australia are among those counties who ratified the CRPD, as well as developed additional local polices and initiatives to provide further guidance on meeting the healthcare needs of people with intellectual disability (Trollor et al., 2016).

In acknowledgement of the policies outlined above, researchers and clinicians from the disability and healthcare fields developed and implemented a wide range of interventions aimed at reducing health disparities and inequities experienced by people with intellectual disability. These interventions acknowledge the biopsychosocial-spiritual (BPSS; Engel, 1997;1980; Wright et al., 1996) framework of health with advances made in the biological (Balogh et al., 2016), social (Simplican et al., 2015), and spiritual (Ault et al., 2013) aspects of health. However, upon further examination, the psychological aspect of health has remained widely unaddressed in the lives of people with intellectual disability. Treatments focus primarily on psychotropic medications (Lewis et al., 2002; Lunsky, et al., 2013) with a marked absence of research examining the application of therapeutic interventions for people with intellectual disability and mental health symptoms in the United States (see Chapter 2). As gatekeepers to health, it is vital to understand the role of healthcare professionals in facilitating the biopsychosocial-spiritual health and well-being of patients with intellectual disability.

The identified gaps in the literature regarding the BPSS health of people with intellectual disability, also impact the available curriculum used to prepare healthcare professionals to best care for these patients (Lennox et al., 1997; Trollor et al., 2016). Where there is training taking place, it seems to happen primarily within specific disciplines or specializations (e.g., pediatric and psychiatric care) rather than across all healthcare training (Kahtan et al., 1994). Additionally, content covered is focused almost exclusively on the medical components of disability (i.e., diagnosis and treatment procedures), disregarding the non-medical supports and services vital to one's health (Kahtan et al., 1994). As a result, healthcare professionals consistently report feeling ill equipped to adequately meet patients with intellectual disability's BPSS health needs (Sahin & Akyol, 2010; Tervo & Palmer, 2004). A sentiment that is echoed by patients with intellectual disability and caregivers alike (Ali et al., 2013).

This critical review provides a synthesis of the current relevant research regarding the role of healthcare professionals in facilitating the BPSS health of people with intellectual disability. It begins with understanding the role of providers' attitudes toward intellectual disability and current research. Then, the chapter shifts to understanding the role of mental models (Johnson-Laird, 1983) of disability, by outlining the medical model (Shogren et al., 2017) and the evolution of the multidimensional model of context (Schalock et al., 2020). The chapter concludes with a discussion of opportunities for future research. Specific attention is paid to needed studies grounded in the multidimensional model of context and how this will help shape healthcare professionals' approaches to caring for people with intellectual disability.

Healthcare Provider Attitude Toward Disability

The World Health Organization (2011) and U.S. Surgeon General (DHHS, 2002) identified healthcare providers' attitudes as a significant barrier to equitable healthcare for people with intellectual disability. While there is not one agreed upon definition of attitudes (Rao, 2004), McGuire (1985) provided a framework for which it can understand and examined. McGuire's framework operationalizes attitudes as affective, behavioral, and/or cognitive in nature. Meaning that attitudes are formed, reinforced, and changed based on an individual's feelings, actions, and thoughts. Zanna and Rempel (1988) further explained that a single attitude can be shaped or developed from one, two, or all three attitudinal components (i.e., affect, behavior, cognition). Therefore, since attitudes can be developed in response to a stimulus that is affective, behavioral, and/or cognitive in nature, measurement of attitudes needs to be multidimensional (Antonak & Livneh, 2000; Findler et al., 2007).

Measuring Attitudes Toward Intellectual Disability

The Attitude Toward Intellectual Disability questionnaire (ATTID; Morin et al., 2013a) is a 67-item measure used to assess attitudes of people without intellectual disability toward intellectual disability. The ATTID was developed from Mental Retardation Attitude Inventory – Revised (Antonak & Harth, 1994), Community Living Attitudes Scale-Mental Retardation (Henry et al., 1996), Pictographic Scale (Nowicki, 2006), as well as the Multinational Attitude Study survey (Burge et al., 2007) and the Montreal Declaration on Intellectual Disability (Lecomte & Mercier, 2004). Morin and colleagues acknowledged that while previous measures to the ATTID exist, none utilized a multidimensional measure (i.e., affect, behavior, cognition) to study attitudes, and none specially assessed intellectual disability (Morin et al., 2013a). Instead, previous measures primarily assessed attitudes toward physical disabilities (Findler et al., 2007; Gething & Wheeler, 1992) or conceptualized attitudes as a single dimension.

Grounded in McGuire's (1985) framework, the ATTID is broken down into three domains (i.e., affect, behavior, cognition). There are five subscales that make up those three domains, (a) *Discomfort* (affect, 17 items), (b) *Sensitivity/Tenderness* (affect; 6 items), (c) *Interactions* (behavior; 17 items), (d) *Knowledge of Capacity and Rights* (cognition; 20 items), and (e) *Knowledge of Causes* (cognition; 7 items). Each of the items in the first three subscales is in response to one of two vignettes. Both vignettes describe a man with intellectual disability, but the individual described in the second vignette has more significant support needs than the individual described in the first vignette. Items in the discomfort subscale assess for participant's emotional response toward several different scenarios based on the vignettes provided. For example, “If Dominic tried to talk to you, do you think you would…” with response options being, to feel wary, afraid, anxious, embarrassed, etc. Items on the sensitivity/tenderness subscale provide response options such as feel sad, touched, moved, and pity. It should be noted that sensitivity/tenderness is not viewed as a positive attitude through the ATTID. Items on the interaction subscale ask participants to respond to the vignettes by rating how likely they would be to interact with the person described in the vignette. For example, would participants agree to adopt, work with, or supervise the individual described in the vignettes. Items in the *knowledge of causes* subscale start with the statement “In your opinion, intellectual and developmental disabilities (IDD) may be caused by:” with items including “malnutrition in the mother” and “problems during birth.” Items in the *knowledge of capacity and rights* subscale being with the statement “In your opinion, the MAJORITY of people with an IDD are able:” with items including “to hold down a job” and “to handle money.” Cut-off scores for the three domains at large (affect, behavior, cognition), as well as the five subscales are as follows: positive attitudes = 1 and 2, neutral attitudes = 3, and negative attitudes = 4 and 5.

To date, the ATTID (Morin et al., 2013a) has been utilized in over 15 different studies to assess attitudes. Populations in previous studies include the general public of Quebec (Morin et al., 2013b), mainstream and special education teachers in Italy (Arcangeli et al., 2020) and Canada (Sermier et al., 2014), Canadian healthcare professionals (Morin et al., 2018), the general public within the United Kingdom (Murch et al., 2017), and U.S. college students (Phillips et al., 2019). Studies have collected data from large sample sizes to establish a base line understanding of a specific population’s attitudes (e.g., the general population of Canada) (e.g., Morin et al., 2013b), and then utilize those baselines scores to compare the scores of sub-populations (e.g., Canadian healthcare professionals) (Morin et al., 2018). Studies also utilized the ATTID to track change in attitudes over time, typically pre- and post- a specific intervention or educational program (e.g., Sullivan & Mendonca, 2017). Reliability is established for the ATTID and each of its five subscales (Morin et al., 2013a). It reports an overall reliability of 0.92 (Cronbach's alpha) with the subscales reporting the following: (a) discomfort 0.89, (b) knowledge of capacity of rights .089, (c) interaction 0.88, (d) sensitivity and tenderness 0.76 and (e) knowledge of causes 0.59 (Morin et al., 2013a).

The ATTID (Morin et al., 2013a) offers several strengths and limitations. The strengths of the ATTID lie the multidimensional examination of attitudes. As established by McGuide (1985), attitudes are comprised of three components (i.e., affect, behavior, cognition). Several of the previously established assessments (e.g., Nowicki & Sanderieson, 2002) only examined behaviors. Additionally, the ATTID is aimed specially at measuring attitudes toward intellectual disability. Other measures available assess attitudes toward disability in general (e.g., Forlin et al., 1999), specific disabilities (Pruett & Chan, 2006), or the inclusion of people with intellectual disability (Loo, 2001). However, no measures focus solely on attitudes toward intellectual disability. A third strength lies in the acknowledgment that people with intellectual disability are a not a homogenous group. By including two vignettes where the people described have varying levels of support needs, Morin and colleagues acknowledged the nuance that differing support needs may impact a participant's attitude.

In addition to the strengths outlined above, the ATTID (Morin et al., 2013a) also presents some limitations. The first, and perhaps most prominent, is that due to its more recent development, there is a lack of longitudinal data showing how a participant's attitude changes over an extended period of time. This is particularly concerning when considering research that indicates age is negatively associated with positive attitudes. Additionally, populations included in studies utilizing the ATTID are limited. The majority of participants are from Canada (Morin et al., 2013a; Morine et al., 2013b; Morin et al., 2018). Additionally, there are no known studies which examine the attitudes of U.S. healthcare professionals who are oftentimes the initial identifiers of intellectual disability and referrers to community-based services.

To date, there is one known study which utilized the ATTID (Morin et al., 2013a) to examine the attitudes of healthcare professionals (i.e., physicians, nurses, and psychiatrists) toward intellectual disability (Morin et al., 2018). When comparing the attitudes of the healthcare professionals to the general population (a sample collected in a previous study), Morin and colleagues (2018) found healthcare professionals reported more positive attitudes for the *Knowledge of causes* and the *Sensibility/tenderness* subscales, but less positive attitudes on the *Interaction* subscale. Meaning that healthcare professionals may gain some basic knowledge regarding causes of intellectual disability in their professional training. Additionally, healthcare professionals are less likely to engage with people with intellectual disability in day-to-day life (outside of their professional role). Morin and colleagues hypothesized this might be in part due to interactions that healthcare professionals have while providing care to patients with intellectual disability. Specifically, they suggested that healthcare professionals are more likely to interact with patients who are experiencing negative health outcomes, and therefore may have a skewed perception of the health of people with intellectual disability. The influential factors that help predict attitudes is an emerging area of focus toward helping reduce health disparities and inequities.

Factors that Predict Attitudes

When considering participants' **age** as a predictor for positive attitudes, Morin et al., (2013b) and Murch et al. (2017) obtained a negative correlation. They found younger participants reported more positive attitude scores than older. In a review highlighting factors associated with positive attitudes toward people with disabilities (as measured by several different assessments), Wang and colleagues (2021) reported that data on the impact of age was inconclusive. Stating that while several studies examined age as a negative correlation, others reported age to be a positive correlation. It should be noted that the studies review by Wang and colleagues (2021) which reported a positive correlation between age and positive attitudes did not utilize the ATTID (Morin et al., 2013a) to measure attitudes. Consequently, the discrepancies regarding the impact of age on attitudes, may be the result of discrepancies in the different measures utilized.

Participant's level of **education**, typically measured categorically (e.g., completed high school, some college completed, 4-year college degree earned), was also found to be a potential factor when considering attitudes toward intellectual disability. Two studies reported higher levels of education correlated with more positive attitudes on the cognition and affect domains of the ATTID (Morin et al., 2013a; Phillips et al., 2019). A third research team reported education was linked to higher attitudes only on the *Knowledge of capacity and rights* subscale (Murch et al., 2017). Given the higher education level of populations included in ATTID studies thus far (i.e., college students, teachers, and healthcare professionals), more research is needed to examine the relationship between level of education and attitudes.

When considering the impacts of **gender** on positive attitudes, results have been inconclusive. Some studies reported a significant relationship (e.g., Morin at al., 2013b; Murch et al., 2017) and others reporting no relationship (e.g., Morin et al., 2018). Specifically, Morin et al. (2013b) reported less positive attitudes on the discomfort subscale for male participants and less positive attitudes on the knowledge of capacity and rights subscale for females. Murch et al.

(2017) reported more positive attitudes on the interaction subscale for male participants. It would appear that there is some relationship between gender and attitudes, but given the lack of consistent findings (i.e., significance reported in differing subscales) more research is needed to further determine the relationship. Additionally, it should be noted that all studies (including those where no significance was found) reporting on the relationship between attitudes and gender, reported only using binary (i.e., male, female) gender categorical data. It is unclear if participants were given the option to select gender related categories other than male and female. More research is needed to examine the relationship between gender and attitudes for participants who do not identify as male or female exclusively.

The participant specific factor that has received perhaps the most examination, is the previous **contact** that a participant had with people with intellectual disability. Contact has been operationalized as: (a) the amount, or *quantity*, of consistent contact that a participant has had with individual(s) with intellectual disability, and (b) the *quality* of the consistent contact that a participant has had with people with intellectual disability. While some studies have exclusively examined the quantity (Murch et al., 2017; Sermier Dessemontet et al., 2014), or quality (Morin et al., 2018), majority examined both (Arcangeli et al., 2020; Gaggioli & Sannipoli, 2021; Morin et al., 2013b; Phillips et al., 2019). Amongst all studies examining the contact factor, there is an agreement that prior contact positively impacts positive attitudes. One hypothesis is that the discrepancies in prior contact when measuring attitudes as an outcome might be better understood by examining the mental model of disability that is promoted and/or reinforced through the context of those prior contacts.

From a Medical to a Contextual Model of Disability

To move research in a direction that honors the BPSS health of people with intellectual disability, it is important to shift how intellectual disability is operationalized from a narrowly focused medical model to a more broadly defined and inclusive mental model. The concept of *mental models* was first introduced by Johnson-Laird (1983) and can be defined as the conceptual view or understanding one holds on any given subject. Mental models have been used within the field of disabilities to describe the various meanings attached to the term disability. Shogren et al. (2017) provided an overview of the various mental models of disability held by society and their evolution over time, as well as the role these mental models play in shaping the way individuals and society at large perceive people with disability. The following is an overview of the evolution of understanding of disability through history from the lens of three different mental models of disability (a) medical model, (b) person-environment fit model, and (c) multidimensional model of context. Additionally, the following vignettes will be utilized to elaborate on the application of each of the medical models.

Vignette A

Amy is a woman in her mid-thirties. She has intellectual and developmental disabilities and lives with two roommates in a metropolitan area. Amy and each of her roommates receive waivered services via their state's department of disability services and have a paid staff member in their home 24/7. Amy is able to independently complete the majority of her daily living tasks (e.g., feeding, bathing, household chores). She primarily needs support when it comes to transportation as she does not have her driver's license. Amy needs to make a trip to her local bank so she can deposit her most recent paycheck. She uses her smart phone to schedule a ride to and from the bank through Send-A-Ride (a car service designated for people with disabilities). Amy's ride arrives on schedule and takes her to the bank. Amy enjoys making trips to the bank without her staff or roommates, as she enjoys having a little time to herself. When Amy enters the bank, she says hello to the same teller she sees every other time when she deposits her paycheck. Amy fills out the deposit form at the counter using the instructions provided on the printed graphic posted at the counter. Amy likes this graphic because it has pictures showing her where to put the correct numbers from her check onto the form. Amy hands her check and completed deposit form to the teller, waits for her receipt, and then goes home in her scheduled Send-A-Ride.

Vignette B

Amy is a woman in her mid-thirties. She has intellectual and developmental disabilities and lives with two roommates in a rural area. Amy and each of her roommates receive waivered services via their state's department of disability services and have a paid staff member in their home 24/7. Amy is able to independently complete the majority of her daily living tasks (e.g., feeding, bathing, household chores). She primarily needs support when it comes to transportation as she does not have her driver's license. Amy needs to make a trip to her local bank so she can deposit her most recent paycheck. Her community does not have a form of public transportation available, so Amy's only option for getting to the bank is to have her staff drive her. Since Amy's house only has one staff member at a time, both of her roommates must also accompany Amy and her staff to the bank. When Amy arrives at the bank, her staff member chooses to go through the drive through of the bank instead of having Amy and both of her roommates all go inside together. The staff member interacts with the teller while Amy sits in the back seat. Since Amy is unable to read the instructions printed on the back of the deposit form telling her what numbers to copy over from her check, Amy's staff member completes it for her.

Medical Model

To understand the medical model of disability, it is important to understand the historical context of the term disability itself. The role of medical professionals in providing supports and services for people with disabilities dramatically has shifted across time. Shogren and colleagues (2017) provided the following historical evolution of the medical model of disability. Prior to the late 1700's, people with disabilities primarily received support in the form of charity (i.e., financial, food, and day-to-day support) from community members, not medical professionals. Providing support to people with disabilities was viewed as the responsibility of the local religious and community organizations, and as a result disability was viewed less as a medical diagnosis, and more as a societal challenge (Shogren et al., 2017).

The early 1800's brought an evolution of the field of psychiatry, that sparked the early development of the diagnosis and classification system still used today (e.g., American Psychiatric Association, 2013). With this classification system, the delineation between people with mental illnesses (i.e., thought at the time to be "curable") and people with cognitive impairments (i.e., understood to be long term) were established. With this primitive diagnostic understanding of the differences between mental health diagnosis and intellectual disability, came the development of formal supports and services (Shogren et al., 2017). As a result, by the mid-nineteenth century, people with intellectual disability were thought to be best served in institutional versus community-based settings (Wehmeyer et al., 2000).

Care provided in institutional settings was modeled after care provided in hospital settings, primary led by healthcare professionals (e.g., psychiatrists, nurses). The development of a diagnostic manual, and the shift to institutional-based services and supports, led to a societal understanding of disability based on the medical model (i.e., disability as a medical diagnosis meant to be treated by healthcare professionals). Given that intellectual disability is a lifelong diagnosis, people with intellectual disability were institutionalized away from their communities and families and resided there for the duration of their lives. Segregation enflamed oppressive beliefs and biases that persons with disability were to be "othered" and did not belong among mainstream society. The combination of medical treatment and segregation led to the conceptualization of a disability is an inherent medical deficit and inhibited people from fully participating in society (Shogren et al., 2017). This deficit-based perspective limited growth in research, services, and training available to healthcare providers on how to care for persons with intellectual disability.

If one were viewing Amy's disabilities from a medical model, they would understand Amy's disability as a fixed inherent trait, and more specifically a deficit. This means that someone would view Amy's disability similar to a chronic illness, which would require Amy to need support constantly, regardless of her environment or individual strengths. Additionally, the medical model of disability would propose that any support needs Amy may have are the direct result of her own inherent deficits, rather than the result of her environment or context. This would be true in both vignettes, despite Amy's seeming capacity for independence in Vignette A.

Person-Environment Fit Model

In contrast to the deficit-based medical model of disability, Shogren and colleagues (2017) provided an alternative view of disability which is based on the person-environment fit understanding of disability. That is the understanding that disability can best be described and understood by examining the way in which an individual's environment does or does not meet their specific support needs. Instead of the individual with a disability having an inherent deficit, the deficit is the result of poor fit between that person and the environment. Using a person-environment fit mental model allows services and supports to be developed and provided that create inclusive environments.

The vignettes described above provide an opportunity for further understanding the person environment fit model of disability. In both scenarios, Amy and her medical diagnosis are the same. However, in Vignette A, Amy's natural supports (e.g., public transportation, graphic explanations at the bank) and environment enable her to complete the task of going to the bank almost independently. In Vignette B, Amy requires significantly more formal supports (i.e., transportation provided by a paid staff member) in order to complete the same task. The person-environment fit model of disability recognizes that Amy's disability is the result of poor environmental fit, rather than an inherent deficit of Amy's. However, Schalock and colleagues (2020) argued that viewing Amy's disability simply in terms of her environment is too reductionistic in thinking.

Multidimensional Model of Context

Viewing disability solely from a person-environment fit fails to acknowledge the greater context of a specific environment. Schalock and colleagues (2020) argued that while the person-environment fit mental model of disability (Shogren et al., 2017) has been beneficial in shaping the view of disability-based supports and services it, "is not sufficient to capture the totality of the circumstances that influence human functioning and valued outcomes" (p. 1). They argued that the multidimensional model of context (Schalock et al., 2020) provides a better framework for understanding disability and achieving desired change. The multidimensional model of context stated that context can be best understood as the combination of three components (a) *multilevel*, (b) *multifactorial*, and (c) *interactive* (see Figure 1 for graphical representation of multidimensional model of context).

The *multilevel* component of context recognizes that a person's environment, at any given moment, can be examined from Bronfenbrenner's (1999) conceptualization of the micro, meso, and/or macro levels (Schalock et al., 2020). The *multifactorial* component of context acknowledges and identifies the specific influential factors within each of the three levels of environment (i.e., micro, meso, and macro). Examples of factors within Amy's micro system might include her interactions with her roommates and paid staff, as well as the physical home she lives in. Factors in Amy's meso system include the specific supports and services available in her community (e.g., public transportation, the agency which provides Amy's staff). Factors within Amy's macro system might include the local, state, and national policies that impact Amy's daily life. When considering the development of appropriate supports and services, the multidimensional model of context acknowledges that changes at the meso level may or may not always be possible, or even useful. In contrast sustainable supports and services that promote overall health, wellbeing, and quality of life are typically implemented at the meso and macro levels (Shogren et al., 2020).

The *interactive* component of context acknowledges the relationship between the multilevel and multifactor components of context (Schalock et al., 2020). Specifically, the interactive component of the multidimensional model of context, "identifies and describes the variety of ways in which levels and factors interact to influence personal outcomes." (Schalock et al., 2020, p. 4). Meaning, that the factors on each level of context (i.e., micro, meso, macro) interact with one another constantly, and over time inform, shape, and change one another. When considering the interactive component of the multidimensional model of context in Amy's life, one might look at the interactions Amy has with the bank teller in both vignettes. In Vignette A, Amy has the opportunity to interact with the bank teller directly. She is able to show the teller that she is capable of depositing her check and may even build a positive relationship with the teller after visiting the bank every other Friday. In Vignette B, Amy has little to no direct contact with the teller, and consequently the teller may never know or understand that Amy could deposit her own checks with some minor adjustments. Over time, these interactions are likely to shape the teller's view of both Amy, and their view of disability at large (Arcangeli et al., 2020; Gaggioli & Sannipoli, 2021; Morin et al., 2013; Phillips et al., 2019). While the teller might not know the formal language of mental models, over time this view of Amy and disability is shaped into a mental model (Johhnson-Laird, 1983). Based on which set of interactions the teller has with Amy, they may develop a mental model of disability that is deficit based and see Amy as inherently flawed. In contrast, the teller may develop a mental model that sees Amy as capable and understands that Amy's environment and context shape her support needs at any given moment. This would be an example of the ways in which Amy's micro system interacts with one another over time to inform and shape each other. Similar insight can be gained by examining the interaction of factors in Amy's meso and macro systems.

When considering Vignette B, an advocate in Amy's life might look at creating change in Amy's meso and macro systems. This could look like advocating for local policy initiatives to fund public transportation, and for signs throughout their community businesses that are inclusive and accessible. If Amy lives in the United States, these local policies might shape and be informed by national policies (i.e., Americans with Disabilities Act, 1990). Each of the three components of the multidimensional model of context (Schalock et al., 2020) can be applied to provide a holistic appreciation for the environment in which an individual lives, learns, works, and plays. This holistic understanding moves beyond the simple acknowledgment of an individual's physical environment (i.e., the buildings and geographical locations), and provides a framework through which the context surrounding an individual can be better understood. The multidimensional model of context can provide valuable insight into understanding healthcare for patients with intellectual disability.

Multidimensional Model of Context and Healthcare

While the multidimensional model of context (Schalock et al., 2020) is recently developed, and as a result have not yet been applied in research, it can provide a valuable understanding when considering the healthcare needs of people with intellectual disability. Specifically, by examining the context of healthcare systems on the micro, meso, and macro levels, and the interactions of factors in each level, research can better understand the mental model of disability being reinforced through those interactions. In the description above, the bank teller's views of disability are shaped by their interactions with Amy, and their interactions with Amy are shaped by the context of those interactions (i.e., a community with and without natural supports for Amy). The same may be true for healthcare professionals. Their perceptions of disability may influence their treatment decisions; therefore, examining their attitudes is critical to understanding their practice patterns and clinical decision making. Given the historical role of healthcare professionals in the development of the medical model of disability (Shogren et al., 2017), and the indication that healthcare professionals attitudes toward intellectual disability may be a barrier to inclusive care (Sahin & Akyol, 2010; Tervo & Palmer, 2004), it is imperative that these interactions and their relationships are explored further to promote inclusive healthcare.

Discussion

Despite significant efforts, people with intellectual disability continue to experience healthcare inequities, specifically when it comes to accessing effective care (Krahn & Fox, 2012). Review of the literature highlights that there are many factors which contribute to and perpetuate these inequities (Ouellette-Kuntz et al., 2005). One category of these factors are provider-specific factors (Ouellette-Kuntz et al., 2005). Both provider attitudes toward caring for patients with intellectual disability and lack of adequate provider training are barriers to equitable health care for people with intellectual disability. The current review presents the theoretical foundation for: (a) understanding and measuring attitudes toward intellectual disability, (b) different mental models of disability and how those models impact the way people understand and interact with people with disabilities, and (c) application of the multidimensional model of context in healthcare. Gaps in the literature highlight how more research is needed to better understand the relationship between the context of healthcare and its impacts on mental models and related attitudes.

Implications for Future Research

Given the recent development of the multidimensional model of context around disability, there is limited literature regarding its application. However, the framework presented by Schalock and colleagues (2020) provides an important conceptual understanding of the role context plays in shaping our understanding of disability. This understanding, combined with the documented health inequities experiences by people with intellectual disability (Krahn & Fox, 2012), has multiple implications for future research. First, baseline research is needed to explore the attitudes of healthcare professionals' attitudes toward intellectual disability. This is particularly important when considering that attitudes have been identified as a barrier to equitable health (Sahin & Akyol, 2010; Tervo & Palmer, 2004), but current research reports that healthcare professionals have relatively positive attitudes toward intellectual disability (Morin et al., 2018). Second, additional research is needed to understand the role interactions with people with disabilities plays in shaping a person's attitude toward intellectual disability. Specifically, given the inconclusive evidence regarding the importance of quantity and quality of previous interactions (Arcangeli et al., 2020; Gaggioli & Sannipoli, 2021; Morin et al., 2013; Phillips et al., 2019), the context of those interactions should be explored. Again, this research must be conducted with healthcare professionals and systems to adequately address current health inequities. Ultimately, there is a need to develop evidence-based interventions, continuing education trainings, and formal educational curriculum for healthcare professionals that promote a multidimensional model of context for understanding disability. Such training should leverage positive provider attitudes as a way to facilitate BPSS health and wellbeing of people with intellectual disability and their families, rather than focusing on physical aspects of health only.

Conclusion

The current literature shows that people with intellectual disability experience widespread health disparities and inequities (Krahn et al., 2012). To address these challenges, research has identified provider-specific factors which serve as barriers to equitable healthcare for people with intellectual disability (Ouellette-Kuntz et al., 2005). Interactions with people with intellectual disability have been identified as a predictor for attitudes (Arcangeli et al., 2020; Gaggioli & Sannipoli, 2021; Morin et al., 2013; Phillips et al., 2019). Additionally, the multidimensional model of context (Shalock et al., 2020) argues that context of interactions must be fully acknowledged to create effective and sustainable supports and services for people with intellectual disability. Utilizing the multidimensional model of context (Shalock et al., 2020) to explore the interactions between healthcare professionals and people with intellectual disability, will allow for a more complete understanding of healthcare professionals’ attitudes.

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Figure 1

Multidimensional Model of Context

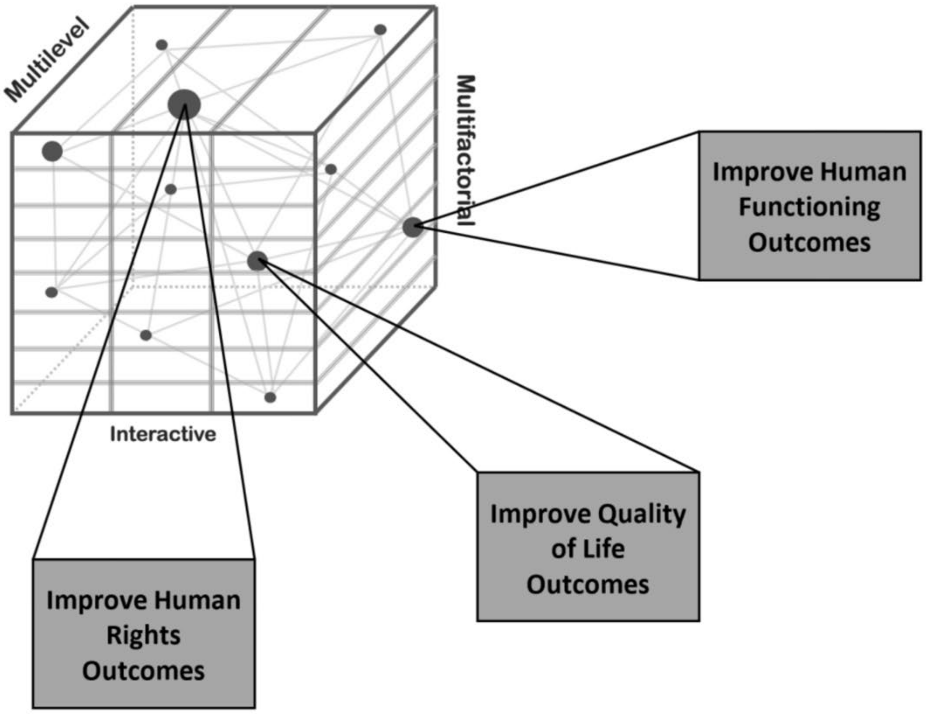

Figure 1. A Multidimensional Model of Context.

Note. This graphic is included with the permission of the American Association on Intellectual and Developmental Disabilities copyright office. See Appendix K.

CHAPTER FOUR: METHODOLOGY

People with intellectual disability experience higher mortality rates, lower life expectancies, and higher rates of complex medical diagnoses, when compared to people without disabilities (Emerson et al., 2012). In addition to these health disparities, people with intellectual disability also experience profound health inequities (Ouellette-Kuntz et al., 2005). Specifically, lower rates of preventative care (e.g., cancer screenings, dental care) (Rimmer & Braddock, 2002) and higher rates of undiagnosed underlying conditions (Janicki et al., 2002). While research points to numerous factors that contribute to these disparities and inequities in health (Mizen et al., 2012), perhaps the most concerning factors are those which are provider-specific (Ouellette-Kuntz et al., 2005). Provider specific factors that have been identified as contributing to the health disparities and inequities experienced by patients with intellectual disability include provider attitudes (Sahin & Akyol, 2010; Tervo & Palmer, 2004) and lack of training and experience (Weise & Trollor, 2017; WHO, 2011).

Despite leading organizations (e.g., WHO, 2011) and public health agendas (DHHS, 2005) pointing to the attitudes of healthcare professionals as a barrier to equitable care, there remains relatively little research exploring these attitudes. What research does exist primarily focuses on assessing provider's attitudes toward inclusion (both community inclusion, and inclusive care practices) (Cornwell, 2004; Lennox et al., 2003). Those studies which have reported specifically on provider's attitudes toward people with intellectual disability found provider attitudes as more positive than the general population (Morin et al., 2018). Due to these inconsistencies, more research is needed to better understand the attitudes of healthcare professionals specifically toward intellectual disability.

Despite calls from researchers over the last two decades (Koch et al., 2001; Troller et al., 2016) there remains a lack of mandated training for healthcare professionals regarding working with patients with intellectual disability. One blaring example is the current lack of required curriculum regarding the care of patients with intellectual disability, in U.S. accredited medical schools (Liaison Committee on Medical Education, 2015). A lack of mandated training across healthcare professions has resulted in physicians (Tervo & Palmer, 2004), nurses (Robey et al., 2001), and mental health professionals (McConkey & Truesdale, 2000) reporting feeling ill-equipped to adequately care for their patients with intellectual disability. Given the integral role of healthcare professionals in providing equitable care for patients with intellectual disability, more research is needed to understand these provider specific barriers, and in developing related effective interventions.

Future Directions

Attitudes

Given the multidimensional nature of attitudes, research which aims to define, understand, and measure attitudes has been identified as particularly challenging and nuanced (Rao, 2004). In an effort to help establish a common understanding of the concept of attitudes, McGuire (1985) provided a framework for attitudes which is comprised of three components (a) affect, (b) behavior, and (c) cognition. Specifically, McGuire stated that attitudes are formed and shaped by stimuli that are affective, behavioral, and/or cognitive in nature. This foundational understanding of attitudes serves as the basis for the development of one of the leading assessments for measuring attitudes toward intellectual disability, the Attitudes Toward Intellectual Disability questionnaire (ATTID; Morin et al., 2013a). In keeping with similar research in the field of disabilities (Wang et al., 2021), the ATTID has been utilized to assess which participant demographic factors (e.g., age, level of education, gender) are correlated to an increase or decrease in positive attitudes toward intellectual disability (Morin et al., 2013b; Morin et al., 2018). Factors that have been identified as predicting positive attitudes include participants who are female and younger (Morin et al., 2015; Murch et al., 2017), as well as participants who identify as healthcare professionals (Morin et al., 2018). However, the majority of research utilizing the ATTID has been conducted with Canadian participants (Morin et al., 2013a; 2013b; Morin et al., 2018), so more research is needed to examine if these predictors remain significant for participants in the United States. In addition to the attitudes of providers, provider education and training have also been identified as barriers to equitable healthcare for patients with intellectual disability (Weise & Trollor, 2017; WHO, 2011).

Healthcare Training in Context

Given the role of medical professionals in perpetrating the historical oppression of people with intellectual disability (Weise & Trollor, 2017; WHO, 2011), special attention must be paid to the context within which future healthcare professionals are trained to work with patients with intellectual disability. Schalock and colleagues (2020) offered the multidimensional model of context as a framework for understanding disability, and a specific individual with a disability's support needs, within a given context. In contrast to previous conceptualizations of disability (Shogren et al., 2017), Schalock and colleagues argued that disability can only be fully understood, and consequently truly effective supports can only be developed, through the examination of context (Schalock et al., 2020). Given the new development of the multidimensional model of context, research has not yet examined its' application to the development of educational programs for healthcare professionals geared toward caring for patients with intellectual disability.

Consequently, we argue that while the multidimensional model of context (Schalock et al., 2020) could provide a useful framework for the development of future education tools, more exploratory research is needed. Specifically, research is needed to establish how the medical context impacts the attitudes and perspectives of healthcare professionals toward intellectual disability itself as well as caring for patients with intellectual disability. In an effort to explore this topic, the current chapter presents the methodology of a mixed methods dissertation exploring healthcare professionals' attitudes and experiences caring for patients with intellectual disability. Details of the methodology include: (a) research questions and hypotheses, (b) description of the study design, (c) recruitment, data collection and analysis procedures, (d) verification strategies, and (e) researchers' use of bias statements.

Research Questions and Hypotheses

The current transformative convergent parallel mixed methods design (Morgan, 2017) utilized a two-part approach. Part 1 involved collecting quantitative data to answer the proposed research question: "What are the attitudes of healthcare professionals toward intellectual disability?" A national sample of healthcare professionals was recruited to complete a demographic survey and the Attitudes Toward Intellectual Disability (ATTID) questionnaire (Morin et al., 2013a). The initial hypotheses for the quantitative portion of the study were:

1. Consistent with previous research (Morin et al., 2015; Murch et al., 2017) we hypothesized that healthcare providers who identify as cis gender female will have more positive attitudes on the discomfort subscale, and less positive attitudes on the knowledge of capacity and rights and the interaction subscales than participants who identify as cis gender male.

2. Consistent with previous research (Morin et al., 2015; Murch et al., 2017) we hypothesized healthcare providers' age will be negatively correlated with participants' attitudes toward intellectual disability.
3. Consistent with previous research regarding Canadian healthcare professionals (Morin et al., 2018) we hypothesized U.S. healthcare providers will report overall higher levels of positive attitudes toward intellectual disability as compared to the general population established in previous research (Morin et al., 2013b).

Part 2 involved collecting focus group qualitative data to answer the following research question: "What are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability?" Data for this portion were collected using a purposive sampling strategy (Patton, 1990) of healthcare providers currently employed in one of three pre-selected clinics. Interviews were obtained through a qualitative focus group interview design (Krueger & Casey, 2015). Participants for Part 2 also completed Part 1 of data collection prior to participating in the focus group interview portion of the study. Due to the nature of qualitative research, hypotheses were not generated prior to the collection of data (Creswell, 2009).

Study Design

The goal of a transformative convergent parallel mixed methods design (Morgan, 2017) is to incorporate several different methodologies to obtain a more complete understanding of the research questions being investigated. The proposed study incorporated: (a) a quantitative self-report survey collected from healthcare professionals across disciplines, and (b) a qualitative focus group interview with primary care providers from three pre-selected clinic locations. The proposed study's purpose is to advance understanding regarding healthcare professionals' knowledge and experiences around caring for adult patients with intellectual disability. The quantitative data serves to provide a baseline understanding of healthcare professionals' attitudes toward intellectual disability and provide a lens through which to interpret the qualitative data (i.e., mean scores of focus group participants regarding attitudes toward caring for adult patients with intellectual disability). Both types of data collection inform the gap noted in the literature but in different ways. While the study gathered descriptive data on participants' attitudes toward intellectual disability, the focus group data offers a thicker and richer description of what is going on behind the quantitative data that was collected.

Creswell (2009) stated that mixed-methods research is best utilized when only using one form of inquiry (i.e., qualitative, or quantitative) will not provide a "complete understanding of a research problem" (p. 4). It is with this understanding that the current mixed method study was designed to explore the attitudes and experiences of healthcare professionals toward intellectual disability. More specifically, use of a self-report validated measure to assess participants' attitudes toward intellectual disability helped to establish a base line understanding of preconceived beliefs toward this population. Then, focus groups help to expand and enhance what is known by inviting participants to share their perspectives and experiences amongst their peers in a relaxed setting (Krueger & Casey, 2015). While there are several different forms of mixed method inquiry (Creswell, 2009), the current study is a transformative convergent parallel mixed methods design. This design reflects how data are being collected and analyzed at relatively the same time, rather than sequentially.

The current mixed methods study was designed from a pragmatic worldview. Creswell (2009) stated that researchers who identify as pragmatists, identify a research question/problem, and then develop a study design that best addresses the question at hand (rather than identifying solely as a qualitative or quantitative researcher). Additionally, a pragmatic world view operates under the assumption, “that research always occurs within social, historical, political, and other contexts.” (p. 11). Consequently, research conducted from a pragmatic worldview may look like a “transformative worldview” and focus on political activism and/or social justice, as is the case for the current study.

The role of theory in quantitative research (i.e., guiding research question and hypotheses formulation) has been widely acknowledged (Creswell, 2009; Thomas, 1997). While historically there has been ambiguity about the role of theory in qualitative inquiry (i.e., is theory present in study development, or only a product study results), Creswell (2009) identified the role of a “causal theory” in qualitative inquiry, stating the theory may shape the development of the research question, as well as the data collection and analysis procedures. Furthermore, Creswell (2009) identified Mertens’ (2009) views on *disability inquiry* (i.e., research that focuses on promoting the self-determination of people with disability) as one of the many theoretical perspectives through which qualitative researchers may conduct their research. It is with this understanding of the role of theory in both qualitative and quantitative research, and the desire to promote the self-determination and inclusion of people with disabilities, that the current mixed methods study was designed.

Setting

There was not a physical location for data collection conducted in Part 1. Instead, social media and email were used to distribute the consent and online surveys to potential participants. Part 2 data collection was conducted at three separate family medicine clinics. All clinic locations: (a) house Family Medicine residency training programs, (b) have one primary location with satellite locations throughout their geographical region, and (c) have an in-house behavioral health team and practice a level three or higher on the Primary Care/Behavioral Healthcare Collaboration continuum (Doherty et al., 1996). Clinic A is in the Southcentral region of the United States, in a metropolitan area (population over 1 million), and consistently hosts 15 family medicine residents, with five core faculty, and has multiple satellite clinics in addition to its' main campus. Clinic B is in the Eastern region of the Unites States, in a community with a population of roughly 42,000, and consistently hosts 30 family medicine residents, with four core faculty. Clinic C is in the Western region of the United State, in a community with a population under 70,000, and consistently hosts 30 residents with 3 core faculty.

Participants

Participants were comprised of two groups. Group A participants only completed Part 1 of the study. Group B participants included participants who completed Parts 1 and 2. Group A participants met the following criteria: (a) employed as a healthcare professional within the United States (e.g., physician, physician's assistant, nurse, mental health professional), (b) provide direct patient care for at least 50% of their job responsibilities, and (c) fluent in written English. Exclusion criteria for Group A were as follows: (a) previous experience working in a healthcare setting designated to care for patients with intellectual disability (e.g., clinics that specialize in diagnosing intellectual and developmental disabilities, behavioral health units that exclusively work with patients with intellectual disability and mental health diagnoses), (b) primarily provide care to non-adult patients (e.g., pediatric providers). For the purpose of this study, healthcare setting was any primary, secondary, and tertiary care location which provides direct patient care.

Based on data collected in 2010 the Agency for Healthcare Research and Quality (National Center for Health Statistics, 2011) estimates there are roughly 163,876 U.S. practicing primary care providers, excluding pediatric providers. Using this population estimate, an ideal sample size of 384 was determined based on a 95% confidence interval and 5% margin of error (Qualtrics, 2021). This sample size is further supported by the design of a similar study which utilized the ATTID (Morin et al., 2013a) to assess Canadian healthcare professionals' attitudes toward intellectual disability which had a sample size of 367.

The U.S. Department of Labor's Bureau of Statistics estimated that there are roughly 552,000 practicing mental health professionals in the United States. There is no data on how many of the 552,000 professionals exclusively work with children, and therefore the total number provides the most accurate sample available. To this author's knowledge no previous studies have utilized the ATTID (Morin et al., 2013a) to examine the attitudes of mental health professionals toward intellectual disability, and therefore cannot add additional insight regarding ideal sample size. Using the U.S. Department of Labor's population estimate (i.e., 552,000), an ideal sample size of 384 was determined based on a 95% confidence interval and 5% margin of error (Qualtrics, 2021). With an ideal sample size for primary care providers of 384 and an ideal sample size of 384 for mental health professionals, the ideal total sample size for participant Group A is 768.

Participant Group B was comprised of those who meet the following criteria: (a) *currently* employed at one of the three healthcare networks described above (e.g., physician, physician's assistant, nurse, mental health professional), (b) provide direct adult patient care for at least 50% of their job responsibilities, and (c) fluent in written and verbal English. Exclusion criteria for Group B were as follows (a) experience, past or current, working in a clinical setting specifically designated for providing care to patients with intellectual disability, (b) primarily provide care to non-adult patients (e.g., pediatric providers). To meet the need for participant group homogeneity (Krueger & Casey, 2015), participants in Group B were grouped based on job title (e.g., medical resident, attending/board certified physician, nurses, mental health provider). Due to an anticipated lack of experience and training around patients with intellectual disability (Trollor et al., 2016) focus groups consisted of 6-10 participants to reach optimal participant engagement (Kreuger & Casey, 2015).

Measures

Demographic information was collected from participants in Part 1 of the study (see Appendix B). Since all participants who engaged in Part 2 of the study had already completed Part 1, demographic information was not collected in Part 2 of the study. Participants were asked to identify their age, gender, as well as questions about their previous and current employment. In addition, participants provided information on previous training locations (i.e., where participants attended the education portion of their medical training), current level of training (e.g., medical resident, licensed practitioner), estimated frequency of working with patients with intellectual disability, and any personal relationships with an individual with intellectual disability.

Attitudes Toward Intellectual Disability

The ATTID questionnaire (Morin et al., 2013a) was administered in Part 1 of data collection (see Appendix C). The ATTID is a self-report measure used to assess participants' attitudes toward intellectual disability and has been used to compare differences in attitudes across groups as well as note within-group changes in attitudes across time (Morin et al., 2013). The ATTID is built on McGuire's (1985) conceptualization of attitudes which states that attitudes are comprised of three dimensions: (a) affect, (b) behavior, and (c) cognition. Consequently, the ATTID is comprised of five subscales that fall within the three dimensions of attitudes (a) *Discomfort* (affect), (b) *Sensibility/Tenderness* (affect), (c) *Interactions* (behavior), (d) *Knowledge of Capacity and Rights* (cognition), and (e) *Knowledge of Causes* (cognition).

The ATTID is split into two sections, with the first section including 30 items focused on general opinions and knowledge of intellectual disability. The second section is comprised of two vignettes with 20 items as a response to each vignette (for a total of 40 items in the second section, and 70 items total across the ATTID). Cognition items are those that come from the first section of the measure. Example cognition items include (a) “In your opinion, the majority of people with an IDD [intellectual and developmental disabilities] are able to handle money?” (knowledge of capacity and rights), and (b) “Do you believe that IDD [intellectual and developmental disabilities] is more common in underprivileged settings?” (knowledge of causes). Affect and behavior items are those that are responding to the vignette portion of the measure. Example affect and behavior items include (a) “If you met Dominic on the street and Dominic tried to talk to you, do you think you would feel comfortable talking to him?” (discomfort-affect), (b) “If you met Dominic on the street and Dominic tried to talk to you do you think you would, feel sad?” (sensibility/tenderness- affect), and (c) “Would you agree to supervise Dominic at your work?” (interactions- behavior).

The items from both vignettes are identical, but three of the items from the second vignette are not scored, leaving a total of 67 scored items for the measure. Each of the 67 scored items are on a 5-point Likert-scale *totally agree* (1), *agree* (2), *neither agree nor disagree* (3), *disagree* (4), *totally disagree* (5). A mean score from 1 to 5 is derived from each of the five subscales. Cutoff scores across the five subscales are as follows 1 or 2 = positive attitude, 3 = neutral attitude, and 4 or 5 = negative attitude. All items in the *Sensibility/Tenderness* subscale and 12 items in the *Discomfort* subscale are reverse coded. All scoring of participants’ responses is done through an Excel workbook created and provided by the developers of the ATTID. Raw data is entered into the Excel sheet which then generates scores on each of the five subscales, and a global (or overall score), for both each individual participant, and the overall sample. This will allow for comparison of scores between different samples (e.g., female participants compared to cis gender male participants) within subscales, as well as overall scores. The ATTID was developed from the following previously validated measures: Mental Retardation Attitude Inventory – Revised (Antonak & Harth, 1994), Community Living Attitudes Scale-Mental Retardation (Henry et al., 1996), and Pictographic Scale (Nowicki, 2006). The ATTID reports an overall reliability of 0.92 (Cronbach's alpha) with the subscales reporting the following reliability *discomfort* 0.89, *knowledge of capacity of rights* .089, *interaction* 0.88, *sensitivity and tenderness* 0.76 and *knowledge of causes* 0.59 (Morin et al., 2013).

Data Collection and Procedures

Prior to initiating the study protocol, approval was obtained from ECU's IRB (see Appendix D for verification). Recruitment for Group A participants followed a snowball sampling method (Biernacki & Waldorf, 1981). Potential Group A participants were contacted via social media (i.e., recruitment information will be shared via Facebook, Twitter, and Instagram) (see Appendix E for examples of recruitment documents). The lead researcher requested social and professional online media groups to share recruitment materials. Professional groups included those geared toward healthcare professionals (e.g., marriage and family therapists, Collaborative Family Health Association, Women in Family Medicine). Requests to post on friends, family members, and colleagues' social media pages/groups were also made. Recruitment for Group A continued until thematic saturation was obtained (Glaser & Strauss, 1967). Recruitment also took place via email (see Appendix E for examples of recruitment documents). The lead researcher sent recruitment emails to personal and professional medical contacts across the country and asked colleagues to share with other professionals who might be interested in participating in Part 1.

Recruitment for Group B participants utilized a convenience sampling (Lavrakas, 2008) method. Potential Group B participants were asked to participate in focus groups during a routine clinic meeting at each of the clinic locations by the lead researcher. Additionally, a study flyer was sent to all potential participants through the email distribution lists at each clinic setting. Once potential focus group participants confirmed an interest in participating, an email invitation to complete Part 1 of data collection was sent by the lead researcher. After potential focus group participants completed Part 1 of data collection, they were asked to participate in Part 2. Focus groups were then scheduled at each clinic location, at a time that is convenient for Group B participants and their respective clinical operations/responsibilities (ideally in conjunction with a previously scheduled lunch seminar). Focus groups were scheduled and structured based on participants, such that participants were grouped together based on their clinical role and level of training and/or education, as well as clinic location. For example, family medicine residents from Clinic A participated in focus groups comprised of only family medicine residents from Clinic A, and practicing physicians from Clinic B only participated in focus groups compromised of other practicing physicians from Clinic B. This served to ensure participant group homogeneity (Krueger & Casey, 2015). This structure also helped to provide an atmosphere where participants could respond openly without the added stress of having a direct supervisor present during the focus group.

Consent was obtained prior to initiating data collection for Parts 1 and 2. Informed consent in Part 1 was administered through REDCap (Harris et al., 2009; Harris et al., 2019), where participants reviewed the initial consent document (see Appendix F) before completing the demographic and the ATTID (Morin at al., 2013a) survey. After consent was completed, participants were given the option to download and save a copy of their informed consent. For part 2, informed consent was gained prior to conducting focus groups. The lead researcher verbally reviewed the consent to participate with each focus group (see Appendix G) and provided an opportunity for all potential participants to ask questions prior to initiating the interview. Potential participants were reminded that participation was completely voluntary and that they could choose to leave the focus group at any time with no consequence. Once verbal consent was obtained, paper copies of informed consent documents (see Appendix G) were be provided to each participant upon request. The lead researcher then turned on the audio recording device and asked participants to verbally consent to focus group participation prior to beginning the interview.

Data Collection

Group A participants were informed in writing of the following data management procedures (see consent in Appendix F) prior to data collection in Part 1. All survey materials collected in Part 1 (i.e., consent, demographic information, and ATTID questionnaire responses) were administered through REDCap (Harris et al., 2009; Harris et al., 2019). Completed surveys were downloaded from REDCap and stored on a password-protected computer network (ECU’s Private Drive). Downloaded data is only accessible by research team members approved through the IRB. Data will be stored on the password-protected computer network for three years (through Spring 2025), per IRB requirements.

Group B participants were required to complete Part 1 of data collection before participating in focus groups (i.e., Part 2 of data collection). Any participants who arrived at focus groups without having completed Part 1 of data collection, were given the opportunity to do so before focus groups began. All participants who complete Part 1 of data collection were asked to create an anonymous participant ID. Participant IDs consisted of the name of the participant's favorite childhood teacher and the number portion of their current address. For example, if the participant's favorite childhood teacher was Mr. Jones, and they currently live at 1234 Mainstreet, the participant's ID would be *Jones1234*. Group B Participants were asked to state their participant ID at the beginning of focus group recordings after consent was obtained. Participant IDs were utilized to match participant responses from Part 1 and Part 2 of data collection while maintaining participant anonymity.

Groups B participants were administered the focus group informed consent verbally (see Appendix G) prior to beginning the focus group interview. Upon receiving participant consent, a semi-structured interview guide was utilized to guide the interviews. The guide was written to ensure consistency in questions asked across groups while maintaining flexibility for focus group conversation to evolve based on participants' responses (Kreuger & Casey, 2015). The semi-structured interview guide was developed through consultation with a co-investigator from one clinic location and the authors and consists of key questions and follow-up prompts in four broad categories (see Appendix H). Focus groups were scheduled at a time that was convenient for focus group participants and was least disruptive to their clinical workflow and training. For this reason, focus groups were conducted through a piggyback format (Kreuger & Casey, 2015) and took place before or after a previously scheduled meeting within the healthcare network. In the case that focus groups were scheduled during a required resident seminar, residents who did not wish to participate in the study were provided with an alternative assignment to avoid being penalized for not participating. Three focus groups were conducted in person, while the remaining three focus groups were conducted virtually for participant safety during the COVID-19 pandemic and convenience. Audio recordings of focus groups was transferred to and stored on a password-protected computer network (ECUs PirateDrive) immediately following each focus group completion. Once audio recordings were successfully transferred to the PirateDrive, they were deleted off the recording devices. Transcripts of audio recordings were obtained from a third-party transcription service (Rev.com). Transcripts utilized pseudonyms to maintain participant anonymity.

At the completion of each individual focus group, participants were given a focus group debrief (see Appendix I). Participants were shown a QR code that they could view through the camera on their phone. A link was provided for any participants who did not have a smart phone. The post-focus group debrief was administered through REDCap (Harris et al., 2009; Harris et al., 2019) and transferred from REDCap (Harris et al., 2009; Harris et al., 2019) to a password protected computer network (PirateDrive) for storage. The collection of post focus groups debrief data allowed for participants to share any additional thoughts that they might not have felt comfortable sharing during the focus group. The open-ended survey also asked participants to share at least one "take away" message that they gleaned from their focus group experience. Finally, the debrief asked participants if they consent to be contacted for member checking regarding preliminary findings. Participants who consented were asked to provide an email address that they could be reached at.

Data Analysis

The current mixed methods dissertation study included quantitative (Part 1 data) and qualitative (Part 2 data) data analyses. Part 1 analysis included a series of independent samples t-tests and correlations to test the previously mentioned hypotheses. Part 2 analysis included

Colaizzi's (1978) phenomenological analysis of focus groups conducted with primary care providers at one of three clinic locations.

Part 1

Participants' de-identified responses to the ATTID (Morin et al., 2013a) questionnaire were transferred from the REDCap (Harris et al., 2009; Harris et al., 2019) survey into the scoring workbook created by the ATTID developers. The workbook provided raw scores for each of the five subscales and a global, or overall, score for each individual participant and the sample at large. Raw scores from the five assessment subscales (i.e., discomfort, knowledge of capacity and rights, interaction, sensibility/tenderness, and knowledge of causes) and the global score were utilized to answer Research Question 1 (i.e., *What are the attitudes of healthcare professionals toward intellectual disability*?). Global scores from the ATTID were transferred to SPSS (IBM Corp., 2020) and all additional statistical analysis was conducted in SPSS. Independent samples t-tests were utilized to address hypothesis 1 (i.e., differences in attitude subscales based on participant gender) and hypothesis 3 (i.e., higher levels of positive attitudes in healthcare professionals compared to the general population). Pearson's correlations were utilized to address hypothesis 2 (i.e., differences in attitudes based on participant age). Additionally, an independent samples t-test was utilized to assess for any group differences in attitudes for Part 1 data between participants from the three different pre-selected clinic locations.

Part 2

Audio recordings were transcribed verbatim by a third-party transcription service (Rev.com). Focus group and post-focus group debrief data analysis utilized Colaizzi's (1978) seven-step phenomenological method (Wirihana et al., 2018), as simplified and outlined in

Sanders (2003). In keeping with Creswell's (2009) views on "causal theory" and Mertens' (2009) definition of *disability inquiry*, all qualitative data will be analyzed through the lens of the medical model (Shogren et al., 2017) and the multidimensional model of context (Schalock et al., 2020).

Familiarizing. The first step of Colaizzi's analysis method, familiarization, included reading through each transcript at least five times to establish familiarity, and then listening to each focus group while simultaneously reading along an additional two times. During this step, the researcher kept a detailed log of personal reflections on each focus group in their reflexive journal. The researcher made additional comments reflecting on evidence of the medical model (Shogren et al., 2017) and the multidimensional model of context (Schalock et al., 2020) throughout transcripts.

Identifying Significant Statements. The second step of Colaizzi's (1978) analysis method focuses on extracting significant statements. Significant statements are those which capture the overall story of the transcript (Sanders, 2003) and directly address the research question at hand (i.e., *What are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability?*). Significant statements may be reflective of the medical model and/or the social-ecological model of disability. After extracting statements from the first focus group separately, the lead researcher and the triangulated research met to review. The lead researcher and the triangulated researcher reviewed the extracted statements to ensure that they accurately captured the overall story of the transcript and were aimed at addressing the research question. The lead researcher and triangulated researcher repeated this process for the remaining transcripts and focus group debrief data.

Forming Meaning Statements. The third step of Colaizzi's (1978) method of analysis focuses on assigning meanings to each of the extracted significant statements. Colaizzi (1978) states that meaning statements balance the need to accurately convey the data while also going beyond the surface value of the words in the transcript. For this step the researchers considered meanings within the context of the medical model (Shogren et al., 2017) and the multidimensional model of context (Schalock et al., 2020). The lead research and the triangulated researcher worked together to assigning meanings to statements extracted from the first focus group transcript. Once the triangulated researcher and the lead researcher were in agreement on the meanings attached to significant statements from the first transcript, the lead researcher assigned meanings to the significant statements from the remaining transcripts and post focus group debrief data in consultation with the triangulated researcher. A peer debriefer was then consulted to collapse and reorganize themes to better address the research question at hand.

Clustering Themes. For the fourth step of analysis, meaning statements were clustered based on similarity to form themes. The lead research worked with the triangulated researcher and peer debriefer as needed, to cluster meanings into themes. Remaining meanings that could not be clustered were maintained and reported in results in order to ensure that results fully capture the essence of the focus group and post focus group debrief data.

Developing an Exhaustive Description. The lead research then developed an exhaustive description of the findings. The exhaustive description provides a comprehensive description of each theme, including quotations and sub-themes when needed. The exhaustive description situates the themes within the context of the medical model (Shogren et al., 2017) and the multidimensional model of context (Schalock et al., 2020), describing what if any evidence of either model was presented in the data.

Producing the Fundamental Structure. For the sixth step of analysis the lead research developed a fundamental structure of the phenomenon being explored through focus groups and focus group debrief data (i.e., caring for adult patients with intellectual disability). The fundamental structure captures the "essence" of the phenomenon and provides a clear description of the findings.

Validating the Findings. The seventh, and final step of analysis focused on verification. The fundamental structure was shared with all focus group participants who completed the focus group debrief and agreed to be contacted via email with a request for feedback. All relevant feedback was taken into account and adjustments were made to the exhaustive description and fundamental structure where needed.

Verification Process

Lincoln and Guba (1985) provided four broad criteria for establishing trustworthiness in phenomenological inquiry (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. Each of the four criteria have individual strategies that can be embedded within a study design to establish trustworthiness. The current study utilizes the following strategies.

Credibility

Five specific strategies, developed by Lincoln and Gub (1985), for establishing the credibility required for trustworthiness include the following: (a) triangulation, (b) peer debriefing, (c) negative case analysis, (d) referential adequacy, and (e) member checking. The current study utilized multiple forms of triangulation (Lincoln & Guba, 1985) to establish credibility. First, multiple focus groups were conducted allowing for multiple sources of information (i.e., participants) to address the overarching research question. Additionally, utilizing a mixed methods design also allowed for multiple sources of information (i.e., quantitative, and qualitative data) aimed at answering the overarching research question. Finally, a triangulated researcher was utilized throughout the qualitative analysis procedures (as outlined above) to offer two sources of analysis. The current study also utilized peer debriefing, where in the lead researcher met with a peer to process study processes and findings periodically throughout the duration of the study. Member checking was the final strategy enacted to establish trustworthiness through credibility. As outlined above member checking is the final step in Colaizzi's (1978) phenomenological analysis and involved sharing preliminary findings with focus group participants for confirmation. The lead researcher sent preliminary findings to those participants who agreed to participate in member checking procedures.

Transferability

Lincoln and Guba (1985) encourage use of thick description to establish transferability of the study's findings. Thick descriptions provide the reader with ample detail to determine if the study is applicable to their setting/population. The lead researcher described in great detail the design of the study, including the participants and procedures, as well as the results yielded. This will allow future readers to determine transferability based on their own setting and population variables (e.g., setting, time, demographics).

Dependability and Confirmability

To establish trustworthiness through dependability and confirmability (Lincoln & Guba, 1985) the lead researcher completed an audit trail (Halpern, 1983). The audit trail includes raw data (e.g., focus group recordings and observation notes), a reflexive journal (maintained throughout the duration of the study), and analysis memos (embedded into the qualitative analysis process). The reflexive journal included entries on the lead researcher's reactions and reflections throughout the research processes (e.g., reactions to focus groups experiences, reflections on study findings). Analysis memos from both the lead researcher and the triangulated researcher provided reflections on data interpretation. Analysis memos aid in replicating the study and understanding how researcher biases and epoche (i.e., bracketing) were accounted for throughout the data collection and analysis phases. This helped to trust that the phenomenon is described in terms of its own inherent system of meaning.

Statements of Bias

Lead Researcher

The lead researcher views disability, including intellectual disability, as a natural part of human diversity, and as such believes that people with intellectual disability should have the right to equitable and beneficial health care. Additionally, this researcher recognizes that historical oppression perpetrated by medical professionals (Wehmeyer et al., 2000) in many ways continues to actively impact the way that people with intellectual disability experience health care today. As a result of both personal and professional relationships and experiences, this researcher is committed to promoting inclusive healthcare for people with intellectual disability. The current study is an extension of the lead researcher's commitment to promoting inclusive health care and therefore may be impacted by the view stated above.

When considering expectations/hypotheses for the qualitative portion of the study, the lead researcher expected to find minimal evidence of the multidimensional model of context of disability. Instead, the lead researcher expected that the majority of healthcare professionals view disability as an internal fixed trait, and specifically as a deficit. Furthermore, the lead researcher anticipated that healthcare professionals would share experiences where they perceive a patient's disability diagnosis as a barrier or hindrance to providing primary care (even if the patient's treatment is not directly related to the patient's disability). This anticipated process is similar to the phenomenon that researcher's term "trans broken arm syndrome" wherein a trans individual experiences challenges getting treated for their broken arm simply because they are trans.

Triangulated Researcher

Aligning with the belief system of the lead researcher, the triangulated research wholeheartedly believes disability is a natural form of human diversity, making up the largest minority population (Institute on Disability, 2011). Despite this, the lead researcher recognizes the healthcare system as a source of support or oppression and believes mental models of healthcare professionals dictate the outcome of care and overall wellbeing of people with intellectual disability. The triangulated researcher aligns with the social-ecological model of disability recognizing that disability occurs at the intersection of human functioning and environmental demands. In their personal experience, the triangulated researcher has witnessed first-hand deficit-based mental models of disability within the field of healthcare and fully expected the current research to demonstrate a deficit-based mental model of intellectual disability creating barriers to healthcare and overall wellbeing.

Summary

The primary aims of this study were to (a) establish an understanding of the attitudes of U.S. healthcare professionals toward intellectual disability utilizing the ATTID (Morin et al., 2013b) and (b) explore the experiences of healthcare professions that impact the care they provide to adult patients with intellectual disability through the lens of the multidimensional model of context (Schalock et al., 2020). This study adds to the current gap in literature regarding provider-specific barriers to equitable health care for people with intellectual disability. Furthermore, findings from this study will support the future development of effective training for providers in caring for patients with intellectual disability.

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CHAPTER 5: EXPEREINCES OF PRIMARY CARE PROVIDERS CARING FOR PATIENTS WITH INTELLECTUAL DISABILITY: A QUALITATIVE STUDY

The deinstitutionalization movement in the 1960's (Hewitt et al., 2013) resulted in a shift in the format through which people with intellectual disability receive healthcare (i.e., from institutional-based to community-based care). This movement was the result of a series of class action lawsuits filed primarily by parents in an effort to end the wrongful treatment and segregation of people with intellectual disability (Hewitt et al., 2013). While this shift in services was life altering for people with intellectual disability and their supporters, there was seemingly little to no change in the way that community-based healthcare providers were trained and provided services. Notably, nearly 60 years later there remains little to no training requirements for primary care providers working with patients with intellectual disability (Liaison Committee on Medical Education, 2015). This lack of training has resulted in healthcare providers "driving without a map" when providing care for patients with intellectual disability (Sisirak et al., 2016). As a result, providers feel ill equipped and inadequately trained to meet the support needs of patients with intellectual disability (Sahin & Akyol, 2010; Wilkinson et al., 2013). While medical research that explores the experiences of patients with intellectual disability is sparce (Feldman et al., 2013), Ali and colleagues (2013) reported that patients and support persons agree providers do not have the tools and skills necessary to adequately meet their healthcare needs.

Toolkits and training resources developed for primary care providers over the past ten years offer guidelines for caring for patients with intellectual disability (The National Curriculum Initiative in Developmental Medicine, 2010; University of Tennessee Boling Center for Developmental Disabilities, 2014). Despite these resources, people with intellectual disability continue to experience profound health disparities and inequities (Burke at al., 2018; Krahn et al., 2006). One hypothesis for the continued gap can be explained, in part, by the perpetuation of medical model of disability in healthcare (see Devlieger et al., 2003 for an explanation of the medical model of disability). The medical model of disability does not account for the context within which healthcare takes place (Schalock et al., 2020). Instead, it situates disability as an inherent deficit of the person (Devlieger et al., 2003) resulting in a lack of patient agency and additional contextual barriers.

When providers operate from a medical model of disability, they prescribe treatment that is aimed at addressing the disability itself (e.g., every patient with autism should receive applied behavior analysis therapy). Conversely, the multidimensional model of context (Schalock et al., 2020) offers an alternative lens through which providers can better meet the healthcare needs of their patients with intellectual disability. When viewing healthcare through the multidimension model of context, providers can support patients based on their unique goals, environments, and supports needs (e.g., this patient is experiencing dysphagia, so treatment speech therapy is recommended). Proponents of the multidimensional model of context (Schalock et al., 2020) argue, that failing to take a person with a disability’s context into account when identifying support needs, healthcare related or otherwise, results in insufficient supports and services. Within the context of healthcare, insufficient supports and services can lead to outcomes such as continued mortality rates that are significantly higher than the general population (McCarron et al., 2015). In order to effectively address this gap in need and services being provided, it’s important to explore the experiences of healthcare professionals who are providing the services and understand their perceptions of the care being provided.

The current study was designed to understand the experiences and perspectives of primary care providers in a training context around caring for people with intellectual disability. In the present study, residency training programs were focused on specifically because they offer a unique opportunity to identify what research and resources are being utilized to train healthcare professionals in real time. Rather than exploring the training experiences of healthcare professionals who perhaps received their medical training several years prior. This was particularly important when considering the significant shifts in healthcare delivery for patients with intellectual disability over the last 60 years (Hewitt et al., 2013). A focus group design (Kreuger & Casey, 2015) served as the qualitative method of inquiry used to explore the following research question, "What are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability?"

Methods

Participants

Participants for the current study met the following inclusion criteria: (a) employed as a healthcare professional (e.g., physician, physician's assistant, nurse, mental health professional), at one of the three IRB approved clinic locations (b) provide direct patient care for at least 50% of their job responsibilities, and (c) fluent in written English. Exclusion criteria were the following (a) previous experience working in a healthcare setting designated to care for patients with intellectual disability (e.g., clinics that specialize in diagnosing intellectual and/or developmental disabilities, behavioral health units that exclusively work with patients with intellectual disability and mental health diagnoses), and (b) primarily provide care to non-adult patients (e.g., pediatric providers).

Faculty, staff, and residents were recruited from the three participating healthcare clinics and focus groups were conducted by location. Participation was voluntary and no punitive consequence were made as a condition for non-participation. Groups were organized based on participant role, such that residents were not in focus groups with faculty or other clinic staff, and clinic staff were not in groups with faculty or residents. This structure was developed to ensure that participants did not experience negative outcomes from participation. Specifically, since residents and staff were asked to reflect on their clinical training experience, it was imperative that faculty (responsible for providing training) were not included in the same group as residents and staff.

A total of 48 focus group participants across all resident, faculty, and staff focus groups participated in the study. Each focus group ranged from 5 to 10 participants. In the resident focus groups (4 total) there were 31 participants combined. The one faculty focus group had five participants (all from the same clinic). There was one focus group comprised of seven behavioral health team members (all from the same clinic), and one focus group comprised of five clinic staff (all from the same clinic). Due to the convenience sampling procedure utilized, the variation in size of resident class, and scheduling limitations at clinic C, equal representation of faculty, staff, and residents was not achievable. See Appendix J for additional participant demographic information.

Recruitment

Approval for the current study, as part of a larger mixed methods design study, was obtained from the Institutional Review Board (IRB) at East Carolina University and Medical Center (see Appendix D). A convenience sampling procedure (Lavrakas, 2008) was utilized to recruit participants from one of three clinic locations. All three clinic locations (a) house Family

Medicine residency training programs, (b) have one primary location with satellite locations throughout their geographical region and (c) have an in-house behavioral health team and practice a level three or higher on the Primary Care/Behavioral Healthcare Collaboration continuum (Doherty et al., 1996; Heath et al., 2013). Clinic A is in the Southcentral region of the United States, in a metropolitan area (population approximately 1 million), and consistently hosts 15 family medicine residents, with five core faculty. Clinic B is in the Eastern region of the Unites States, in a community with a population of roughly 42,000, and consistently hosts 30 family medicine residents, with four core faculty. Clinic C is in the Western region of the United State, in a community with a population under 70,000, and consistently hosts 30 residents with 3 core faculty.

Data Collection

Participants were asked to complete demographic survey prior to participating in focus groups (see Appendix B). A total of seven focus groups were conducted between October 2021 and January 2022. Four of the seven focus groups were conducted virtually due to COVID-19 restrictions with Clinic B and C, and the final three focus groups were conducted in person at Clinic A. A semi-structured interview guide (see Appendix H) was utilized to conduct focus groups to ensure consistency while still allowing for the discussion to evolve naturally within each group (Kreuger & Casey, 2015). Focus groups ranged in time from 31 minutes to 57 minutes, for an average of 42 minutes. Focus groups were audio recorded and these recordings were stored on a password protected computer network. All participants were de-identified in the transcripts to protect their confidentiality.

Data Analysis

Focus group data were analyzed utilizing Colaizzi's (1978) seven-step phenomenological method. Transcripts were performed by a third-party transcription service (Rev.com) and then checked for accuracy by the lead researcher who conducted the focus groups. The primary and triangulated researchers read each transcript in its entirety prior to initiating data extraction. Then, each worked to identify significant statements from each transcript separately, coming together to ensure interrater agreement was being achieved. Meaning statements were then attached to each significant statement with the agreement and consultation of the peer debriefer as needed. Initial analysis yielded nine themes with a total of 12 subthemes. After consultation with the peer debriefer, themes were collapsed and reorganized to better address the research question at hand, for a total of six themes and 27 subthemes (see Table 2). The exhaustive description and fundamental structure were then developed from this data. Finally, the fundamental structure was shared with consenting focus group participants to elicit feedback, completing the final step of analysis, member checking.

Credibility

The current study utilized several strategies for establishing trustworthiness (Lincoln & Guba, 1985). The primary and triangulated researcher both completed bias statements (see Chapter 4). They referred to these bias statements throughout the data analysis process to ensure that the data was being accurately interpreted through the participants' experiences. The primary and triangulated research also utilized peer debriefing periodically throughout the analysis process. There were less than 5% coding differences between the primary and triangulated researcher, and interrater agreement was 100% after brief discussion during steps two and three of data analysis. Finally, a detailed audit trail (Halpern, 1983) was maintained throughout the analysis process. Both the primary and triangulated researchers maintained a reflexive journal and utilized analysis memos throughout the analysis process.

Results

Initial analysis yielded 253 significant statements and 40 meaning statements. Consolidation of meaning statements yielded a total of 27 subthemes and six salient themes (a) Patient agency, (b) Communication strategies, (c) Systemic barriers to care, (d) Deficit view of disability, (e) Equitable healthcare and (f) Communication of intellectual disability. A table of themes, subthemes, and illustrative quotes (see Table 2) provides a connection between the raw data and thematic description of participants' experiences. The content below will provide rich descriptions of each theme and corresponding subthemes.

At the beginning of each focus group, participants were asked to define intellectual disability in their own words. While analysis of participants answers did not produce salient themes, due to widespread responses and a general lack of understanding of intellectual disability as a diagnostic term, data were still identified as valuable for conveying participants experiences and answering the research question at hand. Consequently, a word cloud was developed utilizing WordArt.com. The primary and triangulated researchers independently identified words from participants' responses to include in the final word cloud seen in Figure 1. The three words that appeared most often were “delayed,” “average,” and “normal” respectively. The diagnostic definition of intellectual disability has two criteria; significant limitations in (a) intellectual functioning (most frequently measured by intelligence testing) and (b) adaptive behaviors (e.g., conceptual skills, practical skills; American Psychiatric Association [APA], 2013; Schalock et al., 2021). Overall, participants did not convey an understanding the term intellectual disability as a diagnosis, nor did they convey an understanding of these diagnostic criteria (except for one participant). This was evident as participants discussed the various diagnoses of their patients (e.g., cerebral palsy, dyslexia) and wrongly assumed these patients' diagnoses were synonymous with the term "intellectual disability."

It should also be noted that throughout each focus group participants used the word "caregiver" to describe anyone who accompanied a patient to an encounter. "Caregivers" may be a friend, sibling, parent, paid staff, or anyone else accompanying a patient to their appointment. While participants did not reflect on their use of the term "caregiver" (and consequently it is not reflected in the thematic results below) the researchers feel the use is telling and provides important context when considering participants' understanding of patients' day to day lives. Out of respect for the patients being reflected on in the current study, and the understanding that all people utilize supports, but not all people have a "caregiver" the researchers will use the term support person(s) from here on, unless providing a direct quote from a participant.

Patient Agency

Across all seven focus groups, participants discussed challenges and values related to honoring patient agency for patients with intellectual disability. The analysis yielded three subthemes related to patient agency (a) struggle to balance patient agency and safety, (b) bypassing patient agency to engage with support person, and (c) value patients understanding their care experience.

Struggle to Balance Patient Agency and Safety

Participants acknowledged a personal value of wanting to honor patient agency but felt that this value was often in direct conflict with their values regarding patient safety and wellbeing. This observation was witnessed across all interview groups and clinic settings. Participants questioned a patient with intellectual disability's capacity to effectively follow a treatment plan. Participants also worried about engaging patients with intellectual disability to participate in the development and implementation of their care plans. The concern was that it would result in subpar clinical care that was not in a patient's best interest. Participants described struggling with how to find the right balance between honoring their patients' right to agency, and their role as the provider who is tasked with providing effective health care and support. One participant explained this internal struggle by stating:

> This is an internal monologue I have every time I think [about patient agency for patients with intellectual disability] … if the patient is functional enough to live on their own and work, they should have the right to make medical decisions for themselves. But at the same time, if [a patient with intellectual disability] is profoundly diabetic and has uncontrolled blood sugars and needs insulin, at a certain point, you've got to find some way to go about doing that in a way that's safe. And those are the situations that I still don't really know what the right thing to do is.

Participants shared that they valued patient agency. However, they also noted that there is a difference between honoring patient agency among patients with and without intellectual disability. One participant explained, "But if you had a fully cognizant adult [without intellectual disability] who also refused to take their diabetes medications, you wouldn't send them to court to [enforce treatment plan adherence through support persons]."

Bypassing Patient Agency to Engage with Support Person

Participants discussed how patient agency was particularly challenging for patients they identified as "borderline" intellectual disability (e.g., patients who live independently but need support with transportation and/or healthcare). For patients who were not "borderline", providers argued they could more easily justify engaging with support persons in the development and implementation of a treatment plan without such concerns about patient agency. One participant described this by stating, “People who are profoundly developmentally delayed and aren't reliant on themselves to do things, it's easier because you can make whatever treatment plan you want, and the caretaker will manage all of it.” Another participant explained that they, “try to make sure as much as I can that the feelings of the actual person with disability is focused on and that they can feel heard for at least a couple minutes.” Highlighting that even when the patient is not involved in the development of the treatment plan, the participant still tries engaging with the patient and providing a space for the patients’ voices to be heard.

Value Patients Understanding Their Care Experience

Participants described the importance of trying to ensure patients understand their treatment plans and what is happening to them during their care experience. One participant stated, “It's my responsibility to make sure [all of my patients] understand the plan when they leave.” For several participants this part of their role is in direct support of patient agency. Participants explained that while a patient may or may not choose to follow a treatment plan, they as the provider wanted to make sure the patient understood the plan and was then able to make a conscious choice to follow it or not. Participants described this role as particularly challenging when they believed the patient did not have the ability to comprehend the treatment plan. As a result, participants described the difficult task of deciding what to recommend support persons include or exclude in a treatment plan based on their perception of the patients’ ability to comprehend the treatment provided. One participant recalled an experience with a patient, where the participant was trying to determine if they should recommend the patient have a mammogram and Pap smear. They described this dilemma as, “Are you going to subject somebody to tests that may be scary and invasive and it may be challenging to explain why it's being done?” In this case, the participant was trying to determine if it was appropriate to provide routine exams for a patient if that exam would result in the patient being uncomfortable without fully understanding the need for the discomfort.

Communication Strategies

Participants described utilizing a wide variety of communication strategies when communicating with patients with intellectual disability. Overall, they described communication as being a major barrier. One participant conveyed this barrier by stating, “It is difficult dealing with [a patient] with intellectual disability who has trouble communicating with me.” Analysis yielded five subthemes around communication (a) rely on support person to relay patient concerns, (b) paperwork is not a reliable form of communication, (c) unsure of best practice interview methods, (d) continuity of care can facilitate effective communication, and (e) adjusting communication to match patients’ support needs.

Rely on Support Persons to Relay Patient Concerns

Participants explained that support persons were their main source of support when faced with provider-patient communication challenges. One shared, “With an adult who didn't have an intellectual disability, we would be unlikely to involve their parent or caregiver at all. But for someone who does have a disability, that caregiver becomes our central tool.” Another described, “It's almost like working with a translator.” Several participants reflected on what it might be like to try and navigate an encounter with a patient with intellectual disability when a support person was not present. One explained, “I would've been in so much trouble because the patient could hardly speak... I would've just been super stuck and not known what to do.”

Paperwork is Not a Reliable Form of Communication

When supporters were not present to support patient-provider communication, participants were often left to rely on whatever paperwork the patient brought with them to communicate health information. A participant expanded on this challenge, “We have to rely on the paperwork that comes with the patient. And sometimes it's not always accurate.” Participants went on to explain this was particularly common for patients who live in group homes. Group home supporters are paid support staff who may also be accompanying several other patients with intellectual disability at the same time to the healthcare clinic. One or two staff members may bring three or four patients to their appointments and therefore cannot be in the exam room for every patient’s visit. While participants did not identify these encounters as the most common when working with patients with intellectual disability, they did highlight how these encounters can be particularly challenging when it comes to communication and understanding the patients’ health concerns. Specifically, without a support person present the participants had to rely on paperwork to communicate the patient’s health making it challenging to develop an effective treatment plan.

Unsure of Best Practice Interviewing Methods

Participants described being unsure about what the best practice was for interviewing and communicating with a patient with intellectual disability. For example, while providers highlighted support persons as a source of support when navigating communication challenges, many voiced concerns that relying on support persons for communication might not fully meet the patients’ needs. Several described feeling concerned they were, “missing something” by relying so heavily on support person communication, as opposed to direct patient communication. One described this in more detail by saying:

> I think there's also that sense of insecurity from our end, that we're never really sure that we're getting the story right. So, you can't be secure in your decision making because you're not even sure if you got the story correctly. There's always a little doubt there. [Wondering to oneself], "*Did I get all that right?*"

Continuity of Care Can Facilitate Effective Communication

When asked to reflect on instances where there were less patient-provider communication barriers while caring for a patient with intellectual disability, participants discussed the criticality of continuity of care. They described the importance of getting to know patients over several encounters, while also learning communication strategies that were particularly helpful for that specific patient's support needs. One participant explained, "I have one [patient] who is hard to understand, but I've been able to understand him more and more, the more he comes in. So, it is getting easier for me to room him [and do initial assessments]."

Adjusting Communication to Match Patients' Support Needs

Participants who either had previous experience interacting with people with intellectual disability (e.g., working at summer camps for people with disabilities, a sibling), or who had worked with the same patient with intellectual disability over an extended period of time, gave examples of how they as the provider were able to adjust their communication and/or examination process to better match their patients' support needs. One explained that they had learned to utilize visual aids, typically used in a pediatric unit, as an alternative to verbal communication with their adult patients with intellectual disability. This was particularly effective when assessing for the patient's pain level. Another described asking their patient to point to where they were experiencing pain rather than asking the patient to respond verbally. In some cases, participants also described eliciting support person support for ideas on how to navigate their patient’s support needs. One explained this by saying:

> I had a patient that would get very anxious, even during a physical exam. The parent told me that counting out loud was very therapeutic for the patient. So, when I was just listening to the patient’s heart I would have them count out loud with me, and that seemed to help calm the patient down and make them less anxious.

In each of these instances, participants described how making these adjustments allowed for them to complete their tasks more effectively (e.g., history taking, rooming, performing an exam) without having to make significant adjustments to their workflow (e.g., adding in more time for the visit).

Systemic Barriers to Care

Participants discussed what can best be described as systemic barriers and the impact these barriers have on the care patients with intellectual disability receive. Some barriers were unique to patients with intellectual disability while others were barriers across social locations (e.g., race/ethnicity, ability, gender, socio-economic status, age). One provider explained their frustration and hopelessness with systemic barriers by stating, “There's also systemic challenges, that I don't think most of us could ever change… No matter how much money we put in.” These systemic barriers could be sorted in to five subthemes (a) patients experience delays in accessible available community services, (b) need for more resources tailored to patients with intellectual disability, (c) complex pathways to accessing services, (d) unique impacts/potential barriers to integrated care workflow, and (e) unique challenges to accessing care.

Patients Experience Delays in Available Community Services

When thinking about what supports and services are already established in their communities that might serve their patients with intellectual disability, participants discussed a myriad of challenges. One in specific challenge was related to waitlists for services. A participant described this barrier by stating, "...the patient was on the wait list for waivers and obviously that was going to take a long time." While the patient's intellectual disability diagnosis meant they were eligible for Medicaid Home and Community-Based Services (HCBS) in their state, the state's extensive waitlist for HCBS meant that the patient was not currently, and likely would not receive these supports for several more years. These delays contributed to providers' overall feeling that there is a need for more resources (both within their clinics and within their communities at large) that better meet the specific support needs of patients with intellectual disability.

Need for More Resources Tailored to Patients with Intellectual Disability

When asked what they would like to know more about when it comes to caring for their patients with intellectual disability, participants across all seven focus groups said, "resources." They described feeling as though they had very little or no resources to offer their patients with intellectual disability, their families, and their support persons. Some providers wished they knew more about what resources were available. One explained the need for better knowledge of resources specifically for patients with intellectual disability by stating, "If someone comes in with autism, I know the different things that can be beneficial or not beneficial for them, like ABA therapy," and went on to explain that they did not know what, if any, similar resources would be beneficial for patients with intellectual disability. While another provider voiced a similar concern by staying:

> Maybe the resources are less, or they don't exist. It's hard to have to go [into a patient care visit] and say, "*I don't have anything for you*." Not because I don't know it, well sometimes it is because I don't know, but sometimes it's just because it's not there.

Complex Pathways to Accessing Services

When reflecting on systemic barriers to care, participants highlighted that their patients with intellectual disability had access to services that they could benefit from, but these services were not necessarily designed for specifically for people with intellectual disability. For example, one participant talked about transportation barriers for their patients with intellectual disability who utilize a wheelchair. They shared, "Some people can't get here because if they're poor and they're relying on public transportation, they can't use their wheelchair on the bus." This participant highlighted that while the city the clinic is housed in does have transportation resources, access to these resources is complicated for patients who utilize a wheelchair. Another stated, "You can't get someone to come to the patient's house because they're probably not old enough to do home health and there's red tape." Reflecting that home health services may be available but only for those who meet the age requirement.

Unique Impacts/Potential Barriers of Integrated Care Workflow

Given that each of the clinic settings practiced some level of integrated behavioral health care (Doherty et al., 1996; Heath et al., 2013), participants reflected on the effectiveness of their clinic workflow when caring for patients with intellectual disability. They highlighted that while their workflow may not completely meet the behavioral health needs of their patients with intellectual disability, it still met some level of need. For example, one participant stated, "A lot of times individuals come to us because they haven't been able to connect with other [behavioral health] services. So, I think that a lot of times we're able to provide something that is need fulfilling.” Others reflected on the barriers that having an integrated workflow might create specifically when supporting patients with intellectual disability. Participants noted that clinic policies around duration and frequency of behavioral health appointments limited the support they were able to provider for their patients with intellectual disability. Many participants discussed that these barriers often resulted in making out-of-clinic behavioral health referrals more often. They also noted that their decision to make a referral was arrived at earlier in the assessment phase of care for patients with intellectual disability, than for patients without intellectual disability.

Unique Challenges to Accessing Care

When reflecting on systemic barriers to care for patients with intellectual disability, participants described family dynamics and dominant language differences as barriers that the sometimes needed to overcome to provide care to the patient with intellectual disability. One participant noted that complex family dynamics and perceived support persons struggling in their role challenged the provider’s ability to care for a patient with intellectual disability. They explained, “We end up playing psychologists at that time... We are trying to figure out if there is some hidden resentment? Or [is the mother thinking] *Oh, this is my fault*.” Another stated, “I wish [the mother of a patient with intellectual disability] liked her own kid a little better.”

Participants also shared how caring for a patient whose primary language is not English, and is a person with intellectual disability, is especially challenging when trying to identify community supports. They stated:

> I work with Spanish speakers, with native speakers, and that is a population that already has limited access to resources. I think when there is the addition of intellectual disability,

> the family may not have access to any sort of support or resources [when they come to our clinic] and so I just feeling at a loss, certainly with that population.

In these instances, it was not that the clinics did not have providers who could speak Spanish (as highlighted above) that was the barrier. Instead, providers consistently noticed their Spanish speaking patients experienced significant barriers accessing what community-based supports and services may have been available due their inaccessibility for Spanish speakers.

Deficit View of Disability

Throughout each focus group, as participants responded to questions and explained their interactions with patients with intellectual disability, it became evident that participants hold a deficit view of disability. This was evident through the language participants utilized to describe their patients such as “not normal” and describing patients in terms of what they were not capable of (e.g., verbal communication, independent ambulation). Analysis around this deficit view of disability yielded five subthemes (a) belief that intellectual disability causes mental illness, (b) belief that intellectual disability is the barrier, (c) dehumanization of patients with intellectual disability, (d) belief that patients with intellectual disability require more effort and, (e) *eternal child* perception.

Belief that Intellectual Disability Causes Mental Illness

Participants across each focus group illuded to an assumption that having intellectual disability causes people to have poor mental health. One participant stated, “A lot of times [patients with intellectual disability] are depressed and down because they don’t really do much.” Another described a patient by saying, “I think as a result of everything, their medical and intellectual disabilities, he does have some degree of depression.” When discussing the complexity of developing a treatment plan for patients with intellectual disability one participant stated, “There’s always a lot of psychotropic medications that are on board.” Despite not being directly asked about the relationship between mental health diagnoses and intellectual disability, it was evident that participants perceived a strong connection.

Belief that Intellectual Disability is the Barrier

When describing intellectual disability as a deficit inherent to their patients, participants also talked about how intellectual disability itself is, “a barrier to accessing [care].” The participant did not further describe how intellectual disability is a barrier to care. However, another participant highlighted this by stating, “Another problem with some intellectual disabilities is they don't know why [to follow a treatment plan]. So why do it if I don't really care for it?” In this instance the participant was explaining that a patient’s intellectual disability might inhibit the patient from understanding the importance of the treatment plan and therefore would not be likely to follow the treatment plan. Across every focus group, participants conveyed similar views by explaining that a patient’s diagnosis of intellectual disability is a significant barrier to care, in addition to the systemic barrier discussed above.

Dehumanization of Patients with Intellectual Disability

Throughout each focus group participants consistently used language such as “they” and “them” to describe their patients with intellectual disability as a homogenous group, alluding to the process of dehumanization. While some participants would catch themselves using such language and make corrections, most did not. One participant conveyed the dehumanization of patients with intellectual disability in healthcare by stating, “You’re just trying to treat them with some sort of humanity and respect, even though it’s easy kind of not to.”

Belief that Patients with Intellectual Disability Require More Effort

Participants described an overall belief that patients with intellectual disability, “Take a lot of extra work.” When asked to elaborate on this belief, one participant explained, “I think it's different that you recognize right away before you walk in that, *I'm going to have to do a lot more*." Participants explained this was primarily related to complex treatment plans (e.g., multiple diagnoses and medication), engaging systems of care (e.g., familial and/or professional support persons) and challenges related to communication barriers (described in detail above).

Eternal Child Perception

Participants across each focus group compared their adult patients with intellectual disability to children. One participant stated, “Or can get someone to believe what their problems are … he would say his stomach hurt kind of like kids don't want to go to school say their stomach hurts.” Explaining a case where an adult patient with intellectual disability had a bowel perforation that ended up being missed by clinic staff due to their belief that the patient was saying their stomach hurt in order to avoid going to work. Another participant described the frequent practice of trying to understand a person with intellectual disability’s “level” of disability by comparing them developmentally to a child when they stated, “*Oh they perform on this kind of level*. But it's like, I don't know what an eighth grader performs like?” Here the participant was reflecting on how this practice of comparison is not particularly helpful when trying to understand how to best interact with a patient. Another provider highlighted their struggle with their internal perception of adults with intellectual disability as children by stating, “I catch myself sometimes talking to [the patient] like a kid, which I know in my heart is not appropriate, but also sometimes, it feels right because [the patient] is talking to me [like a child].”

Equitable Healthcare

As participants across all seven focus groups described the care they provided to patients with intellectual disability, wrestle with concepts around health equity and identified areas in which healthcare for patients with intellectual disability both is and is not equitable. Analysis around health equity yielded five subthemes, (a) adjusted workflow to better meet patient's needs, (b) training and previous experience are beneficial, (c) patient-centered care approaches, (d) acknowledgment of lack of appropriate screening and documentation, and (e) unsure how to best support patients in achieving health goals.

Adjusted Workflow to Better Meet Patient's Needs

Across each focus group, participants describe the ways in which they adjusted their typical workflow in order to better meet the support needs of their patients with intellectual disability. In every focus group, participants talked about how needing more time in order to effectively support their patients. In some instances, participants were able to create more time for their patients without it having a negative impact on the overall clinic's workflow, and other times this was not the case. Regardless of whether more time was available, participants across every group agreed more time would be beneficial. One participant explained this sentiment by stating:

> When you have 20 minutes to meet a patient for the first time, learn their intellectual disability history, see where they are as far as cognition, emotional awareness… That's not something you can do in 20 minutes, in addition to addressing an acute problem.

It should be noted that one participant explained, "I think you would find this in primary care across patients with or without intellectual disability, that everyone would want more time with their patients." In other words, limitations related to time are not exclusive for patients with intellectual disability, but participants unanimously agreed more time would be beneficial.

Formal Training and Prior Experience

When asked what types of formal training had been provided on working with patients with intellectual disability, participants explained they had received very little training, with the vast majority or participants saying they had received, "…zero formal training." Instead, participants described having to learn, "on the fly" how to support their patients. Those participants who did receive training specifically aimed at working with patients with intellectual disability explained that they had chosen to seek out those trainings based on personal interest or identified need. Those participants who did have previous experience interacting with people with intellectual disability outside of a healthcare context (e.g., siblings, participants who had worked at summer camps for people with disabilities) described that they believed their previous experience empowered them to better adapt their communication and examination processes to better fit the support needs of their patients. While reflecting on training experiences, or their lack of, participants from every group stated that they believed training would be beneficial. Chapter six of this dissertation will cover specific training topics and ideas that participants identified as beneficial in detail with specific recommendations.

Patient-Centered Care Approaches

When asked to describe how working with patients with intellectual disability is similar to and/or different from working with patients without intellectual disability, participants started out describing how it was the same. One participant stated, "I don't think there's a difference in whether they have an intellectual disability or not." In these examples, participants were describing how their role, and the assessments and means they used to fulfill their role were the same across all patients. However, participants often then went on to describe the ways in which supporting patients with intellectual disability may be different. This process of starting out saying things were the same, and then eventually describing how they are in fact different was consistent across every focus group. When reflecting on this process of identifying similarities and differences one participant stated, “It’s interesting how things are the same, but different.” This participant was describing how their role was the same but recognizing that doing the same thing for every patient does not result in the same outcome for every patient. This became particularly evident as participants were discussing assessment procedures.

Equitable Screening and Documentation

When asked to reflect on current assessment, diagnostic, and paperwork procedures and how they may or may not be effective for patients with intellectual disability, participants consistently described ineffective screening procedures. One participant highlighted a lack of necessary equipment to collect weight and high for patients who utilize a wheelchair. Another explained challenges related to mental health screening by stating,

> With patients without intellectual disability, it's easier to pick up on maybe some more of the subtle, nonverbal cues that someone might be depressed. Then if you pick up on those cues, you can ask some of those screening questions. Versus someone with intellectual disability you might not pick up on those cues and not screen them.

In this instance the clinic did not have every patient complete a screening for depression, but instead providers initiated screenings if they had concerns. Given this process, the participant was concerned that patients with intellectual disability would not be screened for depression when needed due to differences in non-verbal communication. This was a sentiment echoed by other participants who confirmed they also screened for and initiated treatment for depression and anxiety less in their patients with intellectual disability. Participants explained that this was not due to a misconception that patients with intellectual disability could not have anxiety and depression but instead was due to the participants feeling overwhelmed and unsure about appropriate assessment and medication/treatment procedures.

Another participant highlighted challenges related to screening when describing their role in recommending what preventative care screenings they would or would not recommend for a patient with intellectual disability:

> Now they're older where they're needing routine preventative care things that we would do for other people and having a conversation with their caretakers ... talking to the family, is this something that we want to screen for? If we're maybe not going to treat it?

This participant went on to explain that they were specifically discussing whether or not they should recommend to a support person that the patient have a screening for colorectal cancer, given their assumption that if the screening was positive for cancer, treatment would not be recommended. The participant explained that treatment would not be recommended based on their assumptions regarding the patient's low level of quality of life (as a person with intellectual disability and cerebral palsy) and the further negative impacts that cancer treatment might have on quality of life.

Unsure how to Best Support Patients in Achieving Health Goals

Finally, participants described being unsure of how-to best support patients with intellectual disability in achieving their health goals. One provider explained their overall feeling of inadequacy when working with patients with intellectual disability by stating, "I was thinking just in general is just a feeling of inadequacy. There's got to be someone better than me to help this person, because I don't feel like I'm serving them as well as they deserve." It should be noted that this feeling was only present when working with patients with intellectual disability, not patients across the board. Another participant highlighted this difference by stating, "I feel a lot more prepared treating someone without an intellectual disability at this time. I would definitely need more practice treating and just learning how I can provide care and address the needs for someone with intellectual disability." Across each focus group providers recognized they did not have the training or recourses they needed to feel confident in the ability to effectively support their patients with intellectual disability.

Communication of Intellectual Disability

As participants shared experiences working with patients with intellectual disability a theme emerged around the communication of their patients' intellectual disability diagnosis. Analysis then yielded two communication-related sub-themes, (a) confusion around intellectual disability and (b) conveying the lived experience.

Confusion Around Intellectual Disability Diagnosis

When asked to explain how they knew a patient had a diagnosis of intellectual disability, participants described a wide variety of methods. Participants explained they were often unaware a patient had a diagnosis of intellectual disability before entering an exam room and meeting a patient for the first time. In these instances, the participant would either (a) assume the patient had a diagnosis based on their interaction, (b) suspect a patient had a diagnosis, and confirm suspicion by examining the patient's medical record, or (c) wait for the patient or support person, if present, to report the diagnosis. This process was not only different from clinic-to-clinic across the study, but form patient-to-patient within the same clinic.

Conveying the Lived Experience

Across every focus group, as participants were asked to give examples and describe some of their patients with intellectual disability, it became evident that participants were unsure of what language to use. One participant highlighted this challenge when saying, “[the patient] doesn't have the same abilities as your average person. I shouldn't say a normal person because nobody's normal, but…” Another stated, “[I don’t have] much experience treating these conditions in someone who is low functioning with their intellectual disability, or I don't know if low function is the right word, but low independence with their disability.” In each instance, participants struggled with what language to use to describe the patient they were referring to that would allow the researcher to understand the patients lived experience, but clearly felt it was important to provide some context. Participants often used language such as “level of disability” or “level of functioning” to provide this context.

Exhaustive Description

Throughout every focus group and across every question, participants conveyed a deficit view of disability. This deficit view was evident in the way participants described their patients with intellectual disability, as well as in the ways participants described the care they provided. Specifically, participants described not recommending routine preventative care (e.g., cancer screenings) based on their assumptions around patient quality of life (i.e., support person would not pursue cancer treatment since the patient’s quality of life was already so low due to disability diagnosis). Participants also conveyed a deficit view of disability when they described having to work to treat their patients with intellectual disability with humanity and respect.

In each focus group, participants struggled to find language conveying a patient’s “level” of intellectual disability to the research, when describing specific patient examples. This was isomorphic to the challenges participants described when communicating about their patients to other providers in a clinical setting. When asked to provide a definition of intellectual disability, the top three words used were “delayed,” “normal,” and “average.” Participants also described their desire to honor patient agency but saw this as being in direct conflict with providing effective care, specifically when it came to ensuring patients’ safety. Challenges with provider-patient communication, specifically participants’ assumptions about patients’ ability to communicate and comprehend effectively, led participants to bypass communicating with patients and instead engage in direct communication with support persons. While participants conveyed a value that it is important to treat all patients (with and without disabilities) the same; some recognized that applying care universally, does not lead to the same health outcomes. As was evident when participants discussed challenges related to assessing for and treating mental illness in patients with and without intellectual disability. Finally, in each focus group, participants recognized that their patients with intellectual disability experience unique systemic barriers that negatively impact their ability to receive effective healthcare. Specifically, in every focus group, participants identified the need for significantly more community-based resources uniquely designed to support people with intellectual disability (e.g., mental-health services, transportation supports). Across each theme participants conveyed an overall desire of wanting to support their patients with intellectual disability but struggled to understand how to do so effectively and believed additional training and resources would be beneficial.

Discussion

The aim of this study was to explore the experiences of primary care providers caring for adult patients with intellectual disability. People with intellectual disability continue to experience devastating health disparities and inequities (Burke at al., 2018; Krahn et al., 2006).

The current resources for primary care providers, aimed at addressing these disparities and inequities (The National Curriculum Initiative in Developmental Medicine, 2010; University of Tennessee Boling Center for Developmental Disabilities, 2014) fail to train providers on the importance of context. By understanding the context within which people with intellectual disability live, work, and even receive healthcare, providers can better support the healthcare needs of their patients. Conversely when providers view patients with intellectual disability from the medical model of disability (Devlieger et al., 2003) they fail to see the patient wholistically and provide treatment options that continue to lead to negative outcomes such as significantly higher mortality rates (McCarron et al., 2015).

Findings from the current study highlight the pervasive presence of the medical model of disability (Devlieger et al., 2003) amongst primary care providers across three different family medicine residency training programs. In each focus group, participants consistently described disability as an inherent fixed trait within a person, rather than understanding disability within context (Schalock et al., 2020). This process is particularly evident in the theme "Deficit View of Disability." Perhaps most concerning was the subtheme regarding the dehumanization of patients with intellectual disability. Because participants viewed their patients' intellectual disability as an inherent deficit, they struggled to engage their patients clinically to support patients' medical decision-making rights. This was evident in the study's dehumanizing subtheme where participants talked about it being "easy" to not treat their patients with intellectual disability with humanity and respect. This finding is in line with a large body of research that highlights the dehumanization and mistreatment of people with intellectual disability specifically by healthcare providers (Tilley et al., 2012). It was also evident as participants considered not recommending routine preventative care. In these cases, participants assumed that the quality of life for their patients was so low, simply because they had a diagnosis of intellectual disability, that the patient and support persons would choose end of life care over treatment if cancer was found. This finding is in line with previous research that cites provider beliefs as one of the many reasons cancer screenings are less frequent in patients with intellectual disability (Merten et al., 2015). Future research should work to the root of providers' assumption around quality of life for people with intellectual disability. Future training guidelines and resources should work to empower providers to see ways in which quality of life can be understood and bolstered through a patient's context (Schalock et al., 2020) rather than assumed based on a patients' disability.

In line with previous research (Wilkinson et al., 2013), participants identified major challenges around communication with their patients with intellectual disability. Participants reported frequently opting to communicate with patient support persons, rather than directly with the patient. This finding was also noted in the study done by Ali and colleagues (2013). When considering challenges related to communication specifically, participants described these communicated barriers as a result of the patient's inability to communicate effectively, rather than the result of their (as the provider) ability to understand and/or effectively communicate with the patient. As evidence by the participant quote, "It is difficult dealing with [a patient] with intellectual disability who has trouble communicating with me." Again, future training guidelines and resources should work not to provide healthcare professionals with "tips and tricks" for communication but to understand communication challenges within context. Significantly more research is needed that centers the voices and experiences of the patients with intellectual disability themselves, that conveys patient-identified communication techniques.

Perhaps most telling was the language participants utilized to describe their patients. Participants exclusively described their patients in terms of their perception of the patient's deficits (i.e., viewing the patients through the medical model of disability). The American Psychological Association (2020) and multidimensional model of context (Schalock et al., 2020) say that language should describe someone's support needs, rather than their deficits, as a practice of understanding disability within context, instead of disability as a deficit. For example, when describing a patient one participant said, "no communication to be had" but if they were describing the patient in terms of support needs, they would say the patient, "had extensive communication support needs." This removes the deficit from the person automatically and shifts the focus to supports within the context. Future trainings and resources must support primary care providers in making this mental shift in the way they think about, talk about, and provide healthcare to people with intellectual disability. Research is needed to further understand the utilization of the multidimension model of context (Schalock et al., 2020) as a tool for understanding the healthcare related support needs of persons with intellectual disability.

Limitations

While participants were recruited from three different clinic locations across the United States, there was not equal representation across the clinic locations (i.e., one location housed one focus group while the other two had three each). Additionally, the residents were only represented from two of the three training clinics, minimizing generalizability to a wide range of residency settings across the United States. Participant demographic information was not provided equally across all three clinic locations (see Table 1 for full description of missing information), further impacting generalizability. Due to COVID-19 restrictions four out of seven focus groups were conducted virtually. For each focus group (virtual and in-person) participants gathered in the clinics within which they receive training and provide care. While this allowed for convenience for the participants, it may have also led to participants feeling the need to be less direct than they would have been in a different location.

Conclusion

When considering the effectiveness of community-based healthcare for patients with intellectual disability, the importance of context cannot be overstated. Healthcare professionals played a significant role in the historical mistreatment, abuse, and oppression of people with intellectual disability (Weise & Trollor, 2017; WHO, 2011). When we give healthcare professionals tools such as communication strategies and alternative assessment procedures without examining the mental model through which they utilize these tools, we ignore the context. Future research should work to identify effective techniques and strategies for empowering healthcare professionals to adopt a contextual view of disability over a medical view of disability. Healthcare clinics and training facilities can work to identify ways in which their current workflow (e.g., scheduling, communication, assessment, and history taking procedures) perpetual a deficit view of disability, in order to incorporate system wide, effective change in the services are delivers. Finally, future trainings should work to incorporate an understanding of the context through which healthcare is provided, by acknowledging the important role of the mental model (Johnson-Laird, 1983) through which healthcare providers are operating when working with patients with intellectual disability.

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Table 1

Themes, Sub-Themes, and Illustrative Quotes

Themes	Sub-Themes	Illustrative Quotes
Patient Agency	a) Struggle to balance patient agency and safety	*But if you had a fully cognizant adult [without intellectual disability] who also refused to take their diabetes medications, you wouldn't send them to court to [enforce treatment plan adherence through support persons].”*
	b) Bypassing patient agency to engage with support person	*People who are profoundly developmentally delayed and aren't reliant on themselves to do things, it's easier because you can make whatever treatment plan you want, and the caretaker will manage all of it.*
	c) Value patients understanding their care experience	*Are you going to subject somebody to tests that may be scary and invasive and it may be challenging to explain why it's being done?*
Communication Strategies	a) Rely on support persons to relay patient concerns	*I would've been in so much trouble because the patient could hardly speak... I would've just been super stuck and not known what to do.*
	b) Paperwork is not a reliable form of communication	*We have to rely on the paperwork that comes with the patient. And sometimes it's not always accurate.*
	c) Unsure of best practice interview methods	*Did I get all that right?”*
	d) Continuity of care can facilitate effective communication	*I have one [patient] who is hard to understand, but I've been able to understand him more and more, the more he comes in. So, it is getting easier for me to room him [and do initial assessments].*
	e) Adjusting communication to match patients’ support needs	*I had a patient that would get very anxious, even during a physical exam. The parent told me that counting out loud was very therapeutic for the patient. So, when I was just listening to the patient’s heart I would have them count out loud with me, and that seemed to help calm the patient down and make them less anxious.*

Table 1 Cont.

Themes, Sub-Themes, and Illustrative Quotes

Systemic Barriers to Care	a) Patients experience delays in accessible available community services	*...the patient was on the wait list for waivers and obviously that was going to take a long time.*
	b) Need for more resources tailored to patients with intellectual disability	*Maybe the resources are less, or they don't exist. It's hard to have to go [into a patient care visit] and say, "I don't have anything for you." Not because I don't know it, well sometimes it is because I don't know, but sometimes it's just because it's not there.*
	c) Complex pathways to accessing services	*Some people can't get here because if they're poor and they're relying on public transportation, they can't use their wheelchair on the bus.*
	d) Unique impacts/potential barriers to integrated care workflow	*A lot of times individuals come to us because they haven't been able to connect with other [behavioral health] services. So, I think that a lot of times we're able to provide something that is need fulfilling.*
	e) Unique challenges to accessing care	*I work with Spanish speakers, with native speakers, and that is a population that already has limited access to resources. I think when there is the addition of intellectual disability, the family may not have access to any sort of support or resources [when they come to our clinic] and so I just feeling at a loss, certainly with that population.*
Deficit View of Disability	a) Belief that intellectual disability causes mental illness	*A lot of times [patients with intellectual disability] are depressed and down because they don't really do much.*
	b) Belief that intellectual disability is the barrier	*Another problem with some intellectual disabilities is they don't know why [to follow a treatment plan]. So why do it if I don't really care for it?*
	c) Dehumanization of patients with intellectual disability	*You're just trying to treat them with some sort of humanity and respect, even though it's easy kind of not to.*

Table 1 Cont.

Themes, Sub-Themes, and Illustrative Quotes

Deficit View of Disability cont.	d) Belief that patients with intellectual disability require more effort	*I think it's different that you recognize right away before you walk in that, I'm going to have to do a lot more.*
	e) Eternal child perception	*Or can get someone to believe what their problems are … he would say his stomach hurt kind of like kids don't want to go to school say their stomach hurts.*
Equitable Healthcare	a) Adjusted workflow to better meet patient's needs	*When you have 20 minutes to meet a patient for the first time, learn their intellectual disability history, see where they are as far as cognition, emotional awareness… That's not something you can do in 20 minutes, in addition to addressing an acute problem.*
	b) Formal training and previous experience	*…zero formal training.*
	c) Patient-centered care approaches	*It's interesting how things are the same, but different.*
	d) Equitable screening and documentation	*Now they're older where they're needing routine preventative care things that we would do for other people and having a conversation with their caretakers ... talking to the family, is this something that we want to screen for? If we're maybe not going to treat it?*
	e) Unsure how to best support patients in achieving health goals	*I was thinking just in general is just a feeling of inadequacy. There's got to be someone better than me to help this person, because I don't feel like I'm serving them as well as they deserve.*
Communication of Intellectual Disability	a) Confusion around intellectual disability diagnosis	*Some of the patients who I may not have a verified diagnosis for, are gold who line in some medical assisted environment so I'm making an assumption.*
	b) Conveying lived experience	*[I don't have] much experience treating these conditions in someone who is low functioning with their intellectual disability, or I don't know if low function is the right word, but low independence with their disability.*

Figure 1

Defining Intellectual Disability: A Word Cloud

Note. This image was produced with permission using WordArt.com

CHAPTER 6: A BRIEF REPORT ON THE EDUCATIONAL PRACTICES FOR FAMILY MEDICINE PROVIDERS WORKING WITH PATIENTS WITH INTELLECTUAL DISABILITY[2]

People with intellectual disability continue to experience adverse health outcomes, including but not limited to shorter life expectancy (Bittles et al., 2002) and increased mortality rated\s (McCarron et al., 2015) compared to peers without intellectual disability. Inadequate healthcare provider education has been identified as a major contributing factor to the health inequities and disparities experienced by patients with intellectual disability (Weise & Trollor, 2017; WHO, 2011). A sentiment echoed by healthcare professionals who consistently report feeling ill equipped and inadequately trained to meet the healthcare needs of their patients with intellectual disability (Sahin & Akyol, 2010; Tervo & Palmer, 2004).

To address this educational gap, free online toolkits and resources have been developed by Special Olympics-Health and partners to assist healthcare providers caring for patients with intellectual disability (University of Tennessee Boling Center for Developmental Disabilities, 2014). However, there remain no education requirements for U.S. accredited medical education programs regarding working with patients with intellectual disability (Liaison Committee on Medical Education, 2015). Without educational requirements it is unclear if or in what capacity the current available resources are being used in the training of healthcare professionals (Trollor et al., 2016). Therefore, more research on current training practices is needed to obtain a more complete understanding of what topics are or are not being covered in family medicine residency programs regarding working with patients with intellectual disability. The current study was designed to explore the experiences of primary care providers affiliated with family medicine

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[2] Chapter 6 was written as a breif report on education research in accordance with brief report guidelines for the Family Medicine journal

training programs caring for patients with intellectual disability. The research question for the current study is, *what are the personal and professional experiences of primary care providers that influence how they care for adult patients with intellectual disability?*

Methods

The data collected for this brief report is part of a larger mixed-methods design study, aimed at exploring the experiences of primary care providers caring for patients with intellectual disability. Participants for the qualitative portion of the study, were recruited from three family medicine residency programs distributed across the United States (see Table 1 for setting descriptions). Participants consisted of faculty, residents, and clinical staff (see Appendix J for participant demographics from the larger study, with a breakdown of participants by focus group). Focus groups were conducted virtually, and in person when permitted, due to COVID-19 restrictions. To ensure participant safety and confidence from those who may be evaluators of their work, groups were organized based on participant role. Residents were not in focus groups with faculty or other clinic staff, and clinic staff were not in groups with faculty or residents.

Focus group data were analyzed using Colaizzi’s (1978) seven-step phenomenological method, and qualitative analysis verification procedures included the primary and triangulated researchers, as well as a peer debriefer. After analyzing the data, it became evident that there were two main subsets of results (a) themes regarding experiences caring for patients with intellectual disability, and (b) themes regarding training needs and recommendations. The results from themes regarding experiences caring for patients with intellectual disability are being published in a separate manuscript (see Chapter 5). This brief report will be used to report results on participants’ training experiences for working with patients with intellectual disability, as well as recommendations for improvements in training and accreditation guidelines.

Results

The findings presented below are included under one main theme, trainings, and five subthemes: (a) guardianship process and consent for treatment procedures, (b) mental health assessment delivery and follow-up, (c) knowledge of community resources, (d) communication barriers, and (e) identifying and communicating a diagnosis of intellectual disability. See Table 2 for descriptions and illustrative quotes for each subtheme derived from participant experiences and contributions.

When asked to reflect on their training experiences the vast majority of participants stated that they had no formal training regarding working with patients with intellectual disability. Two participants explained that their only training consisted of having one standardized patient during medical school who portrayed someone with an intellectual disability being seen for an acute gastrointestinal complaint (e.g., appendicitis). These two resident participants reported this experience was helpful and thought it would have been beneficial for others as well. An additional two participants stated that they elected to pursue training through continuing education opportunities received apart from their training programs. The preponderance of participants had no formal training for working with patients with intellectual disability.

The majority of participants discussed how they learned their current skills regarding supporting and caring for patients with intellectual disability “on the fly.” Faculty participants reflected on the challenges a “learning on the fly” approach brings. They commented that, “The downside of [learning on the fly] is that if residents don't have [a patient with intellectual disability] on their schedule, then that learning is not happening.” Meaning, if a resident does not have a patient with intellectual disability on their clinic schedule and did not receive training in their education program (like most participants in this study), they may complete residency without having an opportunity to receive any education at all around working with patients with intellectual disability.

When asked if formal training embedded in their education programs would be helpful, every participant agreed that it would be. When asked what areas or topics would be most beneficial to cover in their curriculum, participants initially stated, “We don’t know what we don’t know.” Reflected on the challenge that they were not even sure what they needed to learn more about, since they currently knew so little.

Discussion

In line with previous research (Sahin & Akyol, 2010; Tervo & Palmer, 2004), participants from the current study unanimously agreed that additional training on working with patients with intellectual disability would be beneficial. Based on their experiences providing care, participants identified five specific trainings areas that would be beneficial. Four of these five topics are those which are covered in resources that have already been developed for primary care providers working with patients with intellectual disability (University of Tennessee Boling Center for Developmental Disabilities, 2014). The one topic that is not covered, but noted as important among study participants, was community resources. Table 3 provides an example for how the training topics identified by participants can effectively be incorporated into the medical education and residency curriculum of family medicine healthcare providers.

Future researchers should continue to study and disseminate effective training tools and resources to prepare healthcare professionals for working with patients with intellectual disability. Additionally, the findings from this study confirm that research is needed to understand effective strategies for incorporating resources in medical education and residency curriculum. Finally, more research is needed to understand the role family medicine providers in navigating the unique systems of support often encompassing people with intellectual disability. Specifically, what is the role of providers in communicating with patients and supporters for adult patients with intellectual disability, and what nuances does guardianship add to this role. Generalizability of the current study is limited due to the small sample size and inclusion of only three clinic locations. Additionally, each clinic location was not equally represented in the final sample (e.g., one clinic location hosted only one focus group, while the other two clinic hosted three each).

Conclusion

The current study demonstrates the need for further development and implementation of training for healthcare professionals working with patients with intellectual disability in primary care settings. Furthermore, the resources and training recommendations already available for primary care providers may not being utilized in current training programs. Consequently, we prose an outline for how to incorporate training and educational activities into the medical education and residency curriculum for family medicine providers.

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Table 1

Clinic Descriptions

	Region	Community Population	# of Core Faculty	# of Family Medicine Residents	# of Focus Group Participants
Clinic A	Southcentral	1,000,000	5	15	17
Clinic B	Eastern	42,000	4	30	24
Clinic C	Western	70,000	3	30	5

Table 2

Theme Descriptions and Illustrative Quotes

Training Content Themes	Theme Description	Illustrative Quotes
Guardianship Processes and Consent for Treatment Procedures	Participants reported a lack of understanding, and a desire to learn more about the overall process of guardianship for adults with intellectual disability. Participants specifically were unclear on: (a) how to determine if a patient had a guardian (if the guardian was not present for the appointment), (b) what the legal procedures would be for someone to become a guardian, and (c) what their role as a healthcare provider could or should be in supporting patients and supporters in navigating the guardianship process.	*How do we make those determinations as to interacting with them and giving them autonomy, versus recognizing they can't process the implications of what we're talking about, and we need to look to a power of attorney or guardian or something like that?* *I would like training on when I need to send someone for evaluation about whether or not they would need a legal guardian slash who the heck I would send them to.*
Mental Health Assessment Delivery and Follow-Up	Participants reported a need for more understanding regarding what assessments were and were not validated for adults with intellectual disability, specifically assessments identifying mental health concerns. Participants also reported being uneasy about administering available assessments due to being unsure about available resources and treatments if results indicated a need.	*[We need to know more about] screeners and then operationally what happens with the results of the screening. Screening is the first step and then the second step is what do we do once we identify that there's a need?* *How do you diagnose depression when our screening asks very deeply insightful question that the patient can't answer for you?*

Table 2 Cont.

Training Content Themes	Theme Description	Illustrative Quotes
Knowledge of Community Resources	All participants reported a need for greater understanding of what community-based resources were available in their geographical region for adults with intellectual disability. Participants did not identify what specific area of resources they wanted to know more about, but instead conveyed a desire to be able to provide a list of supports to patients and their supporters.	*I think one of the biggest challenges is making sure that I've got [the patient] connected in all the right spots, because I feel like it's very easy for those people to get lost in the system sometimes.* *In terms of awareness of local providers, I feel very limited.*
Communication Barriers	Participants described an overall need for training regarding communication with people with intellectual disability. While participants did not describe what kind of training would be helpful (e.g., literacy/developmental level, sign language), they identified that communication was a major barrier.	*I would definitely say, providing training and knowing the different types of intellectual disabilities, and how to communicate best with each of them.* *They didn't specifically teach us how to communicate with folks with intellectual disabilities, I don't think, and I haven't been in a position that has offered training for it. Which would be helpful to know how to differently communicate.*
Identifying and Communicating a Diagnosis of Intellectual Disability	Participants described being in situations where they hypothesized a person might have intellectual disability but did not have a confirmed diagnosis. Participants explained two primary concerns: (a) being unsure what their role was as a provider, and (b) being unsure how to communicate their hypothesis to the patient and/or supporters.	*But if [a parent] came in and said 'My son's not as smart as the other kids,' what do I do? I don't know how [long pause]... I'm not prepared for that conversation.* *But there is an [adult] patient that I don't know if he knows that he's different than other people.*

Table 3

Training Recommendations

	Medical School		Residency Program		
	Year 1	**Year 2**	**Year 1**	**Year 2**	**Year 3**
Guardianship Process and Consent for Treatment Procedures	Lecture from state disability law center on guardianship process for adults with intellectual disability. Including different types of guardianship, alternatives to guardianship, and the process of obtaining guardianship.	Lecture from self-advocate on pros and cons of guardianship (e.g., extra layer of support, versus termination of right to vote).	Review paperwork for clinic, identify location of guardianship notation in EHR, identify local resources for changes in guardianship.	Identify and notate guardianship status in EHR for all patients with intellectual disability. Council patients and supporters on pros and cons of guardianship as needed.	Identify local legal providers who are knowledge regarding guardianship process for adults with intellectual disability, and provide referrals as needed.
Assessment Delivery and Follow-Up	Lecture on validated assessments for anxiety and depression for adults with intellectual disability.	Lecture on polypharmacology, and frequent misuse of psychotropic medications for adults with intellectual disability.	Require experiential practice administering validated anxiety and depression screeners to people with intellectual disability across the lifespan through patient simulations or community-engagement activities.	Administer validated anxiety and depression screeners with patient panel with intellectual disability, with preceptor as needed.	Teach 1st year residents how to administer validate anxiety and depression screeners with patients with intellectual disability, and make appropriate referrals as needed.

Table 3 Cont.

	Medical School		Residency Program		
	Year 1	**Year 2**	**Year 1**	**Year 2**	**Year 3**
Knowledge of Community Resources	Lecture on history Medicaid Home and Community-Based Services (HCBS)	Lecture on day-to-day lives of people based on living arrangements (e.g., family home, independent living, group home) and identifying supporters.	Lunch-and-learn identifying (a) local providers who evaluate and diagnose intellectual disability, and (b) local referrals for HCBS.	Identify support needs for patient panel with intellectual disability identifying patient's support needs, and matching resources based on support needs.	Council patients on Medicaid HCBS process for initiating services.
Communication Barriers	Standardized patient with intellectual disability, for history taking lecture (with and without supporter present).	Lecture from self-advocate on respectful communication when communication differences are present and required experiential practice with people with intellectual disability across the lifespan through patient simulations or community-engagement activities	Review Special Olympics-Health module on communication.	Identify communication supports (e.g., visual aids) available in clinic and utilize as needed.	Lunch-and-learn from local speech and language pathologist covering available resources and services.

Table 3 Cont.

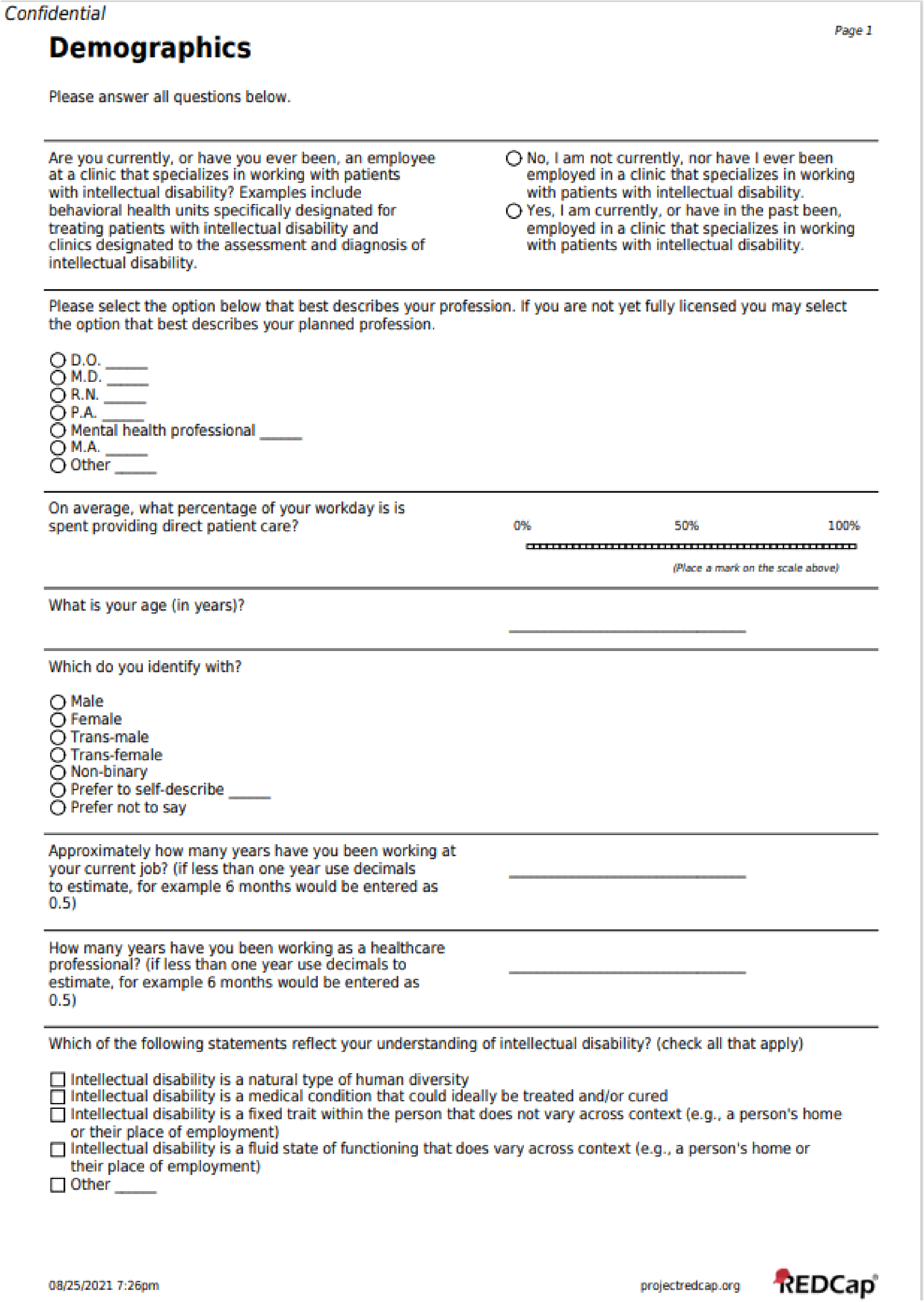
	Medical School		Residency Program		
	Year 1	**Year 2**	**Year 1**	**Year 2**	**Year 3**
Identifying and Communicating a Diagnosis of Intellectual Disability	Lecture on role of healthcare providers in historical oppression and people with intellectual disability and their families.	Lecture on the importance of language in identify formation for families and people with intellectual disability.	Communicate potential intellectual disability diagnosis to patient and/or supporter with preceptor present.	Communicate potential intellectual disability diagnosis to patient and/or supporter as needed.	Lunch-and-Learn case presentation on patient with intellectual disability.

Note. EHR = Electronic health record.

APPENDIX A: ATTITUDES TOWARD INTELLECTUAL DISABILITY QUESTIONNAIRE RESULTS

	Mean	**SD**	**% Positive attitudes (score = 1 or 2)**	**% Neutral attitudes (score = 3)**	**% Negative attitudes (score = 4 or 5)**
Total Sample (n = 81)	2.02	0.94	76.52%	13.84%	9.64
Discomfort	1.83	0.84	85.36%	7.93%	6.71%
Knowledge of Capacity and Rights	1.94	0.83	80.00%	14.74%	5.26%
Interaction	2.09	1.03	72.83%	15.74%	11.43%
Sensibility/Tenderness	2.72	1.08	44.99%	23.11%	31.90%
Knowledge of Causes	2.00	0.83	81.01%	13.07%	5.92%
Clinic A (n = 16)	1.92	0.85	81.52%	12.19%	6.29%
Discomfort	1.62	0.71	93.28%	3.56%	3.16%
Knowledge of Capacity and Rights	1.86	0.69	84.28%	14.72%	1.00%
Interaction	1.98	0.95	78.35%	12.39%	8.27%
Sensibility/Tenderness	2.73	1.06	41.11%	28.89%	30.00%
Knowledge of Causes	1.93	0.68	87.62%	8.57%	3.81%
Clinic B (n = 6)	2.09	0.92	74.63%	15.42%	9.95%
Discomfort	1.86	0.84	84.31%	8.82%	6.86%
Knowledge of Capacity and Rights	1.89	0.67	87.50%	10.00%	2.50%
Interaction	2.31	1.03	60.78%	26.47%	12.75%
Sensibility/Tenderness	2.92	1.05	36.11%	25.00%	38.89
Knowledge of Causes	1.98	0.84	80.95%	11.90%	7.14%
Clinic C (n = 4)	2.38	1.12	57.09%	24.25%	18.66%
Discomfort	1.9	0.95	80.00%	8.82%	10.29%
Knowledge of Capacity and Rights	2.73	1.02	40.00%	38.75%	21.25%
Interaction	2.5	1.26	50.00%	27.94%	22.06%
Sensibility/Tenderness	2.58	1.18	54.17%	12.50%	33.33%
Knowledge of Causes	2.14	0.97	67.89%	21.43%	10.71%

APPENDIX B: DEMOGRAPHICS SURVEY



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Page 1

Demographics

Please answer all questions below.

Are you currently, or have you ever been, an employee at a clinic that specializes in working with patients with intellectual disability? Examples include behavioral health units specifically designated for treating patients with intellectual disability and clinics designated to the assessment and diagnosis of intellectual disability.

○ No, I am not currently, nor have I ever been employed in a clinic that specializes in working with patients with intellectual disability.
○ Yes, I am currently, or have in the past been, employed in a clinic that specializes in working with patients with intellectual disability.

Please select the option below that best describes your profession. If you are not yet fully licensed you may select the option that best describes your planned profession.

○ D.O. ______
○ M.D. ______
○ R.N. ______
○ P.A. ______
○ Mental health professional ______
○ M.A. ______
○ Other ______

On average, what percentage of your workday is is spent providing direct patient care?

0% 50% 100%

(Place a mark on the scale above)

What is your age (in years)? ______________________________

Which do you identify with?

○ Male
○ Female
○ Trans-male
○ Trans-female
○ Non-binary
○ Prefer to self-describe ______
○ Prefer not to say

Approximately how many years have you been working at your current job? (if less than one year use decimals to estimate, for example 6 months would be entered as 0.5) ______________________________

How many years have you been working as a healthcare professional? (if less than one year use decimals to estimate, for example 6 months would be entered as 0.5) ______________________________

Which of the following statements reflect your understanding of intellectual disability? (check all that apply)

☐ Intellectual disability is a natural type of human diversity
☐ Intellectual disability is a medical condition that could ideally be treated and/or cured
☐ Intellectual disability is a fixed trait within the person that does not vary across context (e.g., a person's home or their place of employment)
☐ Intellectual disability is a fluid state of functioning that does vary across context (e.g., a person's home or their place of employment)
☐ Other ______

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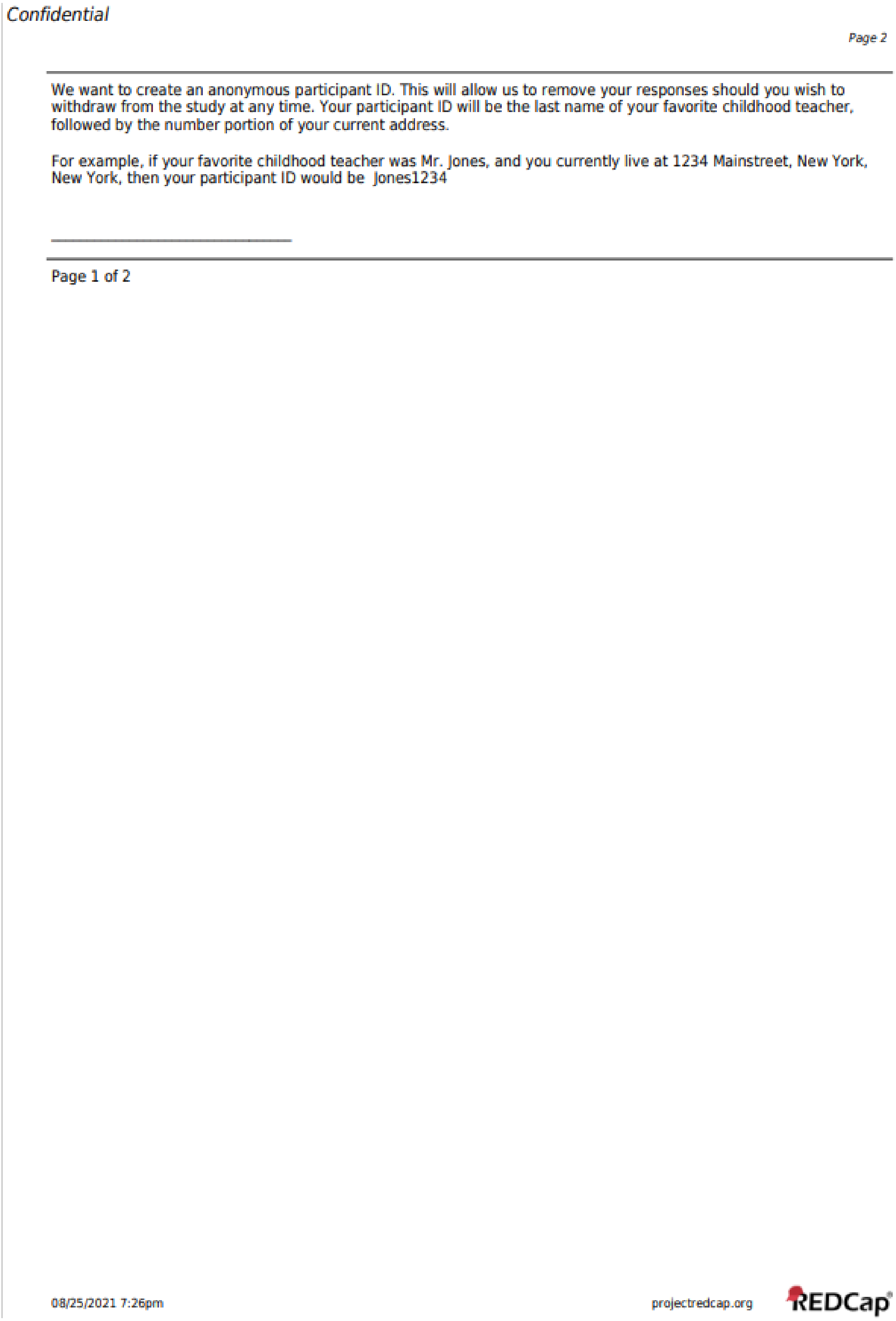

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We want to create an anonymous participant ID. This will allow us to remove your responses should you wish to withdraw from the study at any time. Your participant ID will be the last name of your favorite childhood teacher, followed by the number portion of your current address.

For example, if your favorite childhood teacher was Mr. Jones, and you currently live at 1234 Mainstreet, New York, New York, then your participant ID would be Jones1234

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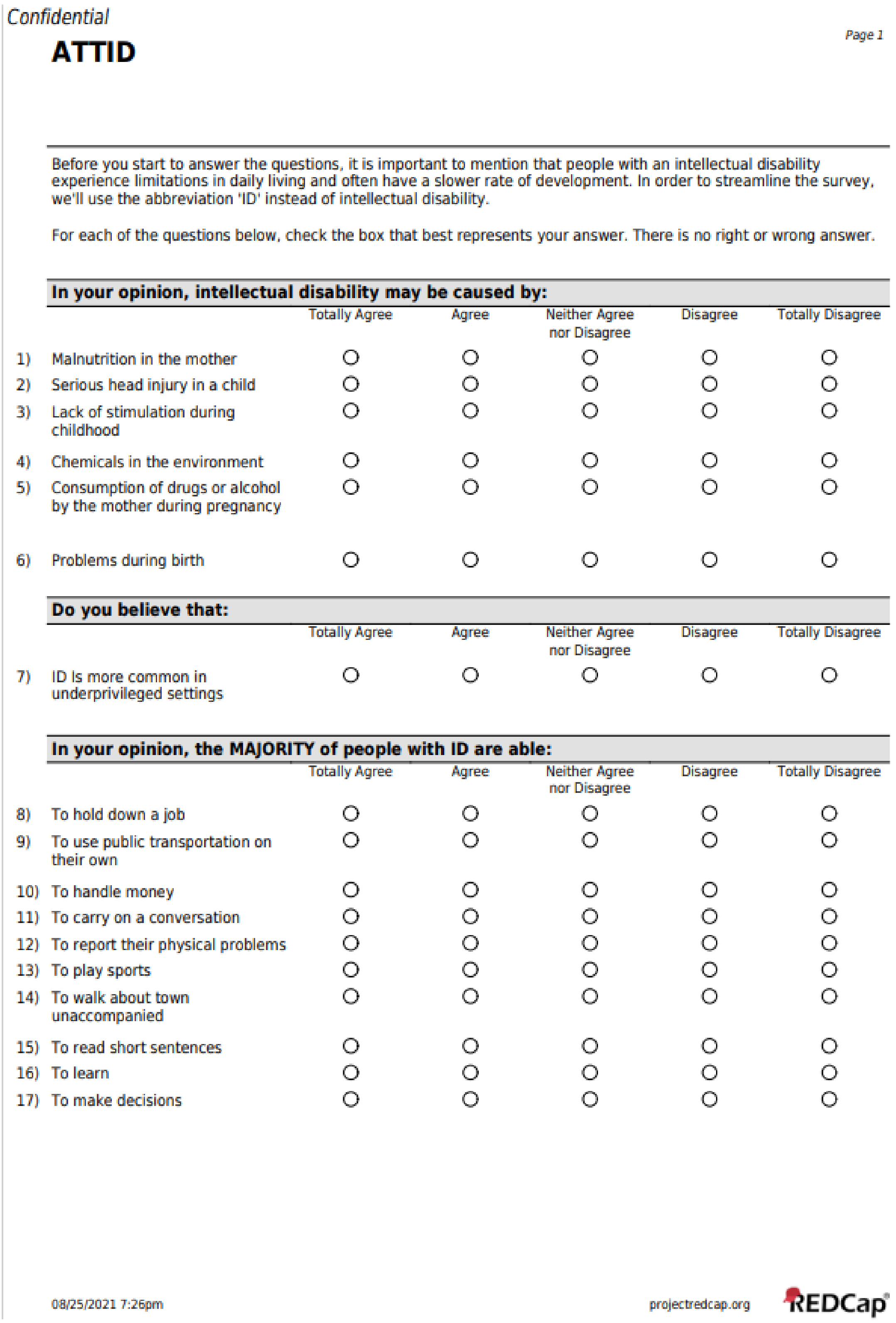
APPENDIX C: ATTITUDES TOWARD INTELLECTUAL DISABILITY QUESTIONNAIRE



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ATTID

Before you start to answer the questions, it is important to mention that people with an intellectual disability experience limitations in daily living and often have a slower rate of development. In order to streamline the survey, we'll use the abbreviation 'ID' instead of intellectual disability.

For each of the questions below, check the box that best represents your answer. There is no right or wrong answer.

In your opinion, intellectual disability may be caused by:

		Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
1)	Malnutrition in the mother	○	○	○	○	○
2)	Serious head injury in a child	○	○	○	○	○
3)	Lack of stimulation during childhood	○	○	○	○	○
4)	Chemicals in the environment	○	○	○	○	○
5)	Consumption of drugs or alcohol by the mother during pregnancy	○	○	○	○	○
6)	Problems during birth	○	○	○	○	○

Do you believe that:

		Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
7)	ID Is more common in underprivileged settings	○	○	○	○	○

In your opinion, the MAJORITY of people with ID are able:

		Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
8)	To hold down a job	○	○	○	○	○
9)	To use public transportation on their own	○	○	○	○	○
10)	To handle money	○	○	○	○	○
11)	To carry on a conversation	○	○	○	○	○
12)	To report their physical problems	○	○	○	○	○
13)	To play sports	○	○	○	○	○
14)	To walk about town unaccompanied	○	○	○	○	○
15)	To read short sentences	○	○	○	○	○
16)	To learn	○	○	○	○	○
17)	To make decisions	○	○	○	○	○

In your opinion, people with ID:

	Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
18) Should give their consent to receive medical care.	○	○	○	○	○
19) Who work should be paid the same wages as other employees even if they are less productive	○	○	○	○	○
20) Have just as much right as people who don't have ID to make decisions about their life	○	○	○	○	○
21) Should have the right to get married	○	○	○	○	○
22) Should have the right to drink alcohol	○	○	○	○	○
23) Should have the right to have sex	○	○	○	○	○
24) Should have the right to vote	○	○	○	○	○
25) Should have the right to have children	○	○	○	○	○
26) Should have the same rights as everyone else	○	○	○	○	○

In your opinion, THE MAJORITY:

	Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
27) Of children with ID should have the opportunity of attending a regular elementary school	○	○	○	○	○
28) Of adolescents with ID should have the opportunity of attending a regular secondary school	○	○	○	○	○
29) Of people with ID should have the opportunity of working in an ordinary workplace	○	○	○	○	○
30) Of people with ID should participate in leisure activities such as a baseball team, the scouts	○	○	○	○	○

For the next few questions, it is important to carefully read both descriptions. After each description, there will be questions about what you will have read.

DESCRIPTION 1 :

Dominic is an adult with ID. Dominic is able to take care of his own health and personal needs (showering, hair, dressing, etc.), but sometimes needs reminding. Dominic is able to carry on a conversation, but has difficulty discussing things that are abstract or complex. Dominic knows how to use the telephone and can write.

If you met Dominic on the street and Dominic tried to talk to you, do you think you would:

	Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
31) Feel afraid?	○	○	○	○	○
32) Feel pity?	○	○	○	○	○
33) Feel sad?	○	○	○	○	○
34) Feel embarrassed?	○	○	○	○	○
35) Experience anxiety?	○	○	○	○	○
36) Feel insecure?	○	○	○	○	○
37) Be wary?	○	○	○	○	○
38) Feel touched, moved?	○	○	○	○	○
39) Feel comfortable talking to him?	○	○	○	○	○

In your opinion:

	Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
40) Would you move away if Dominic was next to you on a bus?	○	○	○	○	○
41) If Dominic asked you a question on the bus, would you answer him?	○	○	○	○	○
42) Would you agree to work with Dominic?	○	○	○	○	○
43) Would you accept Dominic working at your child's daycare center or school?	○	○	○	○	○
44) Would you accept being served in a café by Dominic?	○	○	○	○	○
45) Would you agree to supervising Dominic at your work?	○	○	○	○	○

46)

Would you accept being advised by Dominic in a clothing store?	○	○	○	○	○
47) Would you accept being advised by Dominic in an electronics store?	○	○	○	○	○
48) Would you accept Dominic as your child's friend?	○	○	○	○	○
49) If you wanted to adopt a child, could you adopt Dominic?	○	○	○	○	○
50) If you were a landlord, would you rent to Dominic?	○	○	○	○	○

DESCRIPTION 2 :

Raphael is an adult with ID. He communicates using sounds and gestures. He is able to show by gestures that he needs to go to the toilet. Since Raphael has major coordination problems, he requires constant assistance when he moves around and always has to be accompanied on outings. He also has trouble with various movements. He is able to feed himself with an adapted spoon, but he drops food.

If you met Raphael on the street and Raphael tried to talk to you, do you think you would:

	Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
51) Feel afraid?	○	○	○	○	○
52) Feel pity?	○	○	○	○	○
53) Feel sad?	○	○	○	○	○
54) Feel embarrassed?	○	○	○	○	○
55) Experience anxiety?	○	○	○	○	○
56) Feel insecure?	○	○	○	○	○
57) Be wary?	○	○	○	○	○
58) Feel touched, moved?	○	○	○	○	○
59) Feel comfortable talking to him?	○	○	○	○	○

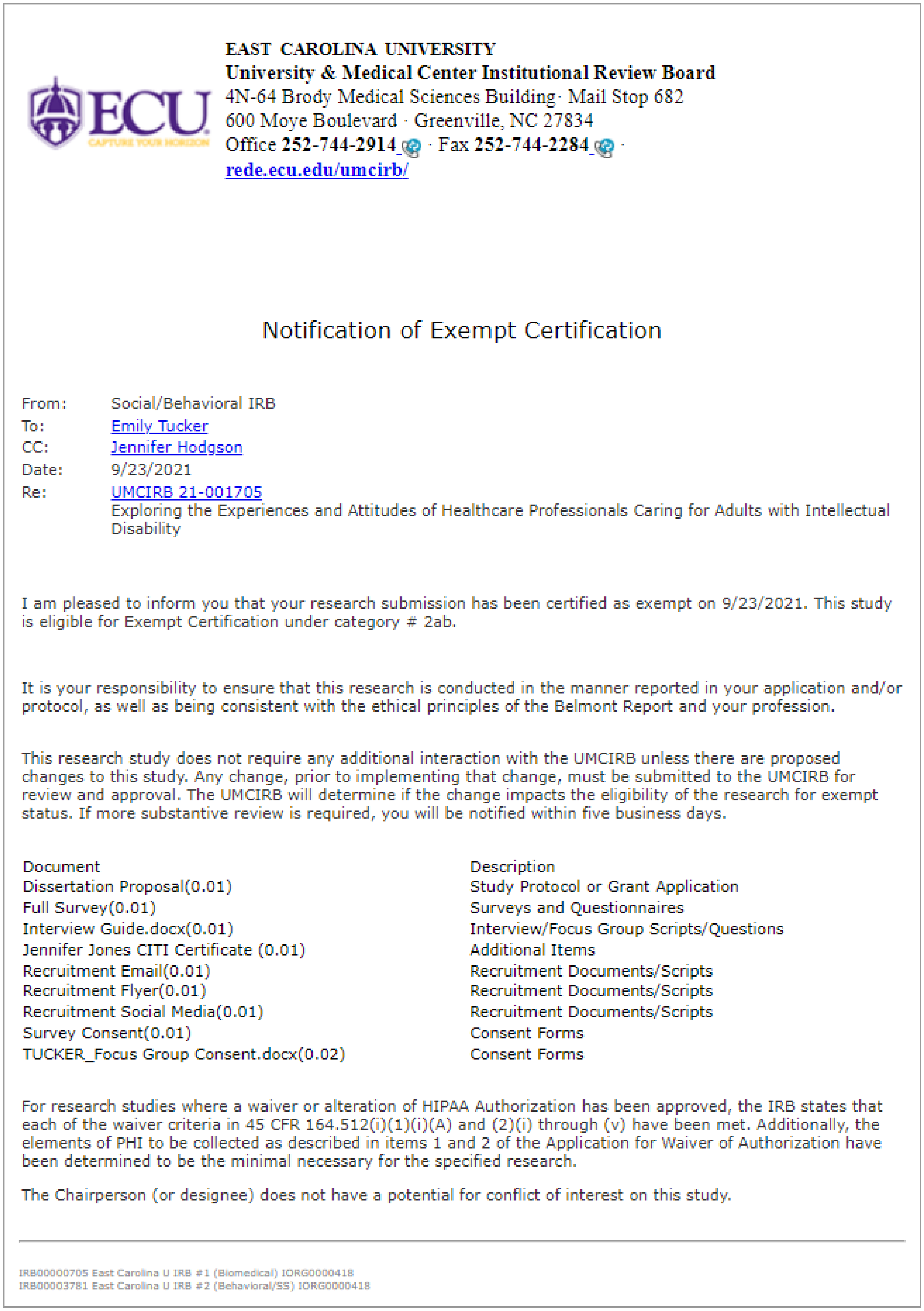
In your opinion:

	Totally Agree	Agree	Neither Agree nor Disagree	Disagree	Totally Disagree
60) Would you move if Raphael was next to you on a bus?	○	○	○	○	○
61) If Raphael asked you a question on the bus, would you answer him?	○	○	○	○	○
62) Would you agree to work with Raphael?	○	○	○	○	○

63)

	Would you accept Raphael working in your child's daycare center or school?	○	○	○	○	○
64)	Would you agree to supervising Raphael at your work?	○	○	○	○	○
65)	Would you accept Raphael as your child's friend?	○	○	○	○	○
66)	If you want to adopt a child, could you adopt Raphael?	○	○	○	○	○
67)	If you were a landlord, would you rent to Raphael?	○	○	○	○	○

APPENDIX D: IRB APPROVAL



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** ·
rede.ecu.edu/umcirb/

Notification of Exempt Certification

From: Social/Behavioral IRB
To: Emily Tucker
CC: Jennifer Hodgson
Date: 9/23/2021
Re: UMCIRB 21-001705
Exploring the Experiences and Attitudes of Healthcare Professionals Caring for Adults with Intellectual Disability

I am pleased to inform you that your research submission has been certified as exempt on 9/23/2021. This study is eligible for Exempt Certification under category # 2ab.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

Document	Description
Dissertation Proposal(0.01)	Study Protocol or Grant Application
Full Survey(0.01)	Surveys and Questionnaires
Interview Guide.docx(0.01)	Interview/Focus Group Scripts/Questions
Jennifer Jones CITI Certificate (0.01)	Additional Items
Recruitment Email(0.01)	Recruitment Documents/Scripts
Recruitment Flyer(0.01)	Recruitment Documents/Scripts
Recruitment Social Media(0.01)	Recruitment Documents/Scripts
Survey Consent(0.01)	Consent Forms
TUCKER_Focus Group Consent.docx(0.02)	Consent Forms

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX E: RECRUITMENT MATERIALS

Are you a healthcare worker, who provides direct patient care?

Researchers at East Carolina University are recruiting healthcare professionals for a dissertation research study exploring the **attitudes of healthcare professionals toward intellectual disability.** Your time and support are deeply appreciated!

Take the with the link below or with the QR code:
https://tinyurl.com/DisabilitiesInHealthcare

QR Code

Who qualifies to take this survey?

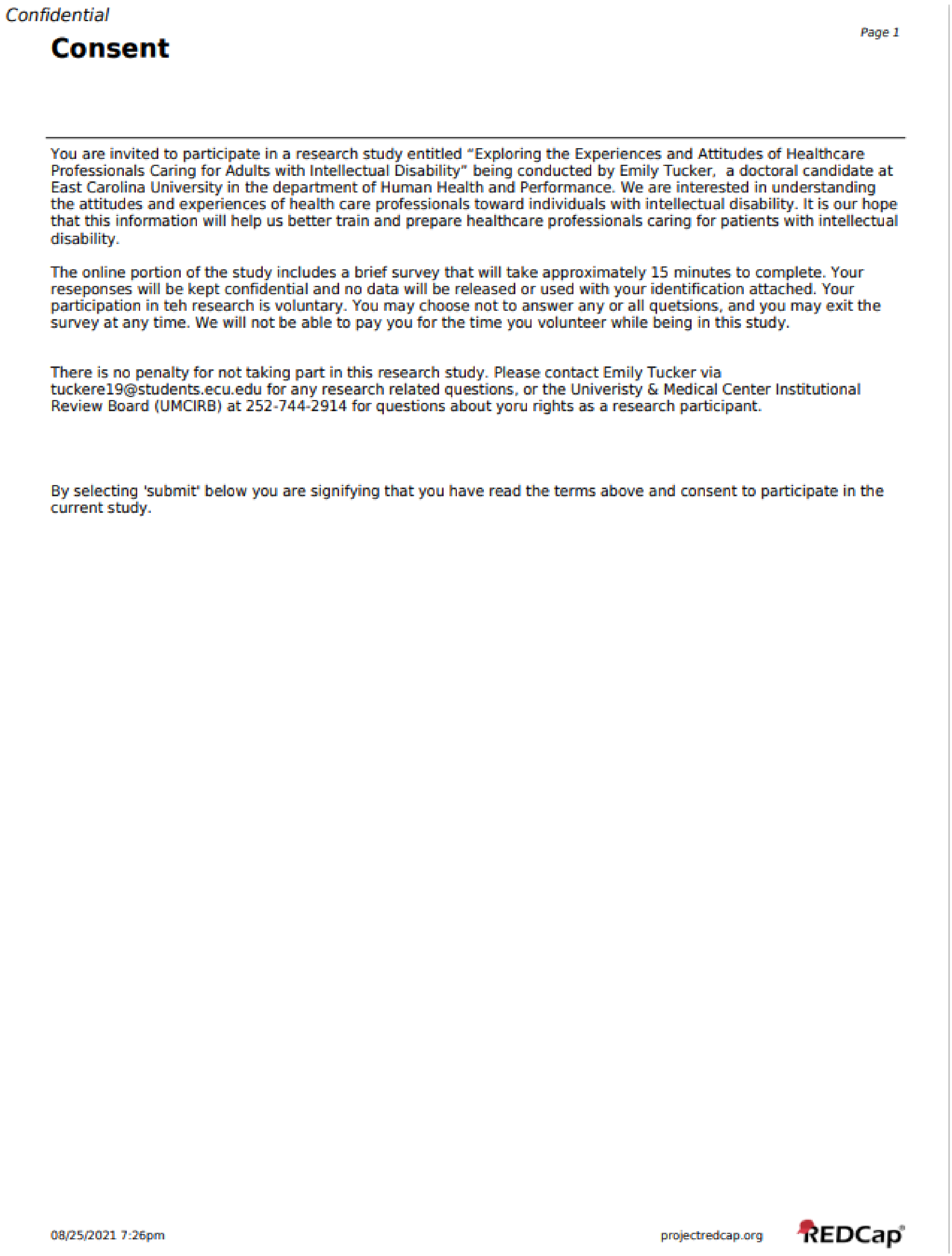
- Currently employed as a healthcare professional in the United States
- Provide direct patient care to adult patients for at least 50% of your job

What to expect?

- They survey should take 10-15 minutes to complete

For additional questions:
Contact Emily C. Tucker (PI)
Tuckere19@students.ecu.edu
IRB# 21-001705

APPENDIX F: CONSENT FOR SURVEY



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Consent

You are invited to participate in a research study entitled “Exploring the Experiences and Attitudes of Healthcare Professionals Caring for Adults with Intellectual Disability” being conducted by Emily Tucker, a doctoral candidate at East Carolina University in the department of Human Health and Performance. We are interested in understanding the attitudes and experiences of health care professionals toward individuals with intellectual disability. It is our hope that this information will help us better train and prepare healthcare professionals caring for patients with intellectual disability.

The online portion of the study includes a brief survey that will take approximately 15 minutes to complete. Your reseponses will be kept confidential and no data will be released or used with your identification attached. Your participation in teh research is voluntary. You may choose not to answer any or all quetsions, and you may exit the survey at any time. We will not be able to pay you for the time you volunteer while being in this study.

There is no penalty for not taking part in this research study. Please contact Emily Tucker via tuckere19@students.ecu.edu for any research related questions, or the Univeristy & Medical Center Institutional Review Board (UMCIRB) at 252-744-2914 for questions about yoru rights as a research participant.

By selecting 'submit' below you are signifying that you have read the terms above and consent to participate in the current study.

08/25/2021 7:26pm

projectredcap.org

APPENDIX G: CONSENT FOR FOCUS GROUP

*Thank you for agreeing to participate in the study entitled "*Exploring the Experiences and Attitudes of Healthcare Professionals Caring for Adults with Intellectual Disability.*" We are interested in understanding the attitudes and experiences of healthcare professionals toward individuals with intellectual disability. I will be asking you question about your personal and professional experiences with individuals with intellectual disability. I have roughly 15 questions which should take us about 45 minutes to an hour to complete. Your responses will be captured on this digital voice recorder.*

There are no right or wrong answers to these questions. All the information you share will remain confidential. After recording, all of the interviews will be sent to Rev.com, a transcription service. Rev.com will transcribe each interview and delete the recording upon returning the transcription back to the researcher. All final transcripts will be de-identified, but in order to maintain confidentiality I ask that you avoid using names and other identifying information, such as age or living location, of patients and/or personal acquaintances.

Your participation in this research is voluntary. You may choose not to answer any and all questions and may stop at any time. If at any time you need to take a break or wish to discontinue your participation in this study please let me know. You have the right to withdraw your responses from the study at any time, for any reason, and without any prejudice. There is no penalty for not taking part in this research study. If you would like to contact the Principal Investigator to discuss this research, please e-mail myself (Emily Tucker) at tuckere19@students.ecu.edu or you may contact my supervisor Dr. Jennifer Hodgson at hodgsonj@ecu.edu.

APPENDIX H: FOGUS GROUP INTERVIEW GUIDE

Thank you for agreeing to participate in this study about the experiences of primary care providers caring for patients with intellectual disability. I will be asking you questions about your own personal experiences with individuals with intellectual disability, questions around any professional training you may have had, and questions around your perceptions of mental health care for individuals with intellectual disability.

If at any time you need to take a break or wish to discontinue your participation in this study, please let me know. As previously mentioned in the informed consent process, I ask that you do your best to either avoid using names to refer to patients and co-workers or use pseudonyms if needed. When we have completed our focus-group I will turn off the recorder and then invite you to participate in a short debrief.

Thank you very much for your investment in helping us to better understand your experiences in caring for patients with intellectual disability.

Section 1: General Experience

- *I am going to start off by asking you about your general experience in providing care to patients with intellectual disability.*
    - (1.1) Please define intellectual disability in your own words.
        - Prompt with "mental retardation" terminology if needed
    - (1.2) In the past year how many patients have you treated with a known diagnosis of intellectual disability?
        - How did you know of their diagnosis? Self-disclosed? EHR documented?
    - (1.3) Without giving identifying information about the patient/family, please describe an experience you have had caring for a patient with intellectual disability.
        - Was there a support person present? What was the presenting problem? Were you able to effectively communicate with your patient?
        - How did you feel during and after the appointment?
        - Reminder: Focus on provider experiences NOT patient characteristics.
    - (1.4) Please describe how treating a patient with intellectual disability is similar to and/or different from treating a patient without intellectual disability.
        - How do you navigate consent? Do you engage in shared decision making around treatment plans/goals?

Section 2: Training and Education Experience

- *In this next set of questions, I am going to ask you about what training you had, either formal or informal, that has best prepared you for your work with patients with intellectual disability.*
    - (2.1) Please describe any and all training experiences you have had specifically around working with patients with intellectual disability.
        - School programs? Internship/residency? Professional development? On the job/day to day?
    - (2.2.) Please describe how prepared you feel to treat patients with intellectual disability in your current clinic. Explain why.

        - Communication barriers. Medication and diagnoses knowledge.

Section 3: Mental Health

- *In this third set of questions, I going to ask you specifically about metal health related care for patients with intellectual disability. Mental health here can include specific diagnoses such a as Anxiety and Depression, as well as broader concepts such as stress, emotional safety and well-being, and trauma.*
    - (3.1) Please describe what if any services and procedures your clinic currently has in place around providing mental health supports to all patients.
        - Screeners? Referrals? On site treatment? Medications?
    - (3.2) Are these services and procedures different for patients with intellectual disability? If so, please describe how.
    - (3.3) Please describe how effective you feel these services and procedures are at meeting the needs of your patients with intellectual disability. Explain your answer with as much detail as possible.

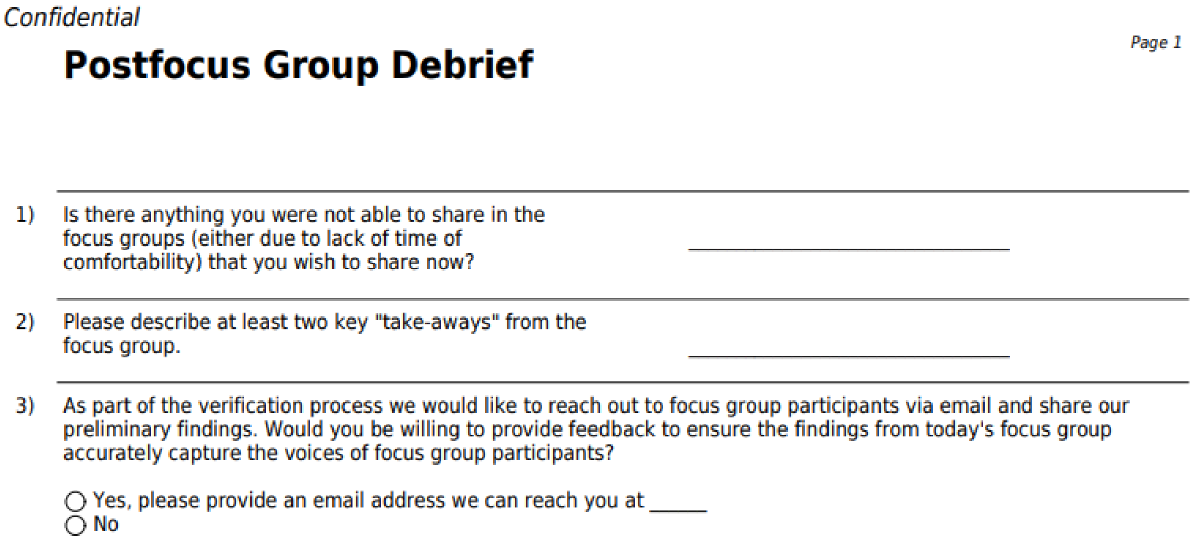
Section 4: Possible Improvements

- *Based on your previous experiences and what we have talked about today.*
    - (4.1) What, if any, changes would you make to your current clinic procedures and workflow to better support patients with intellectual disability?
        - Paperwork? Scheduling procedures? Consent for treatment? Documentation in EHR?

Section 5: Wrapping it Up

- Reflecting back on what you all have shared during our discussion today…
    - (5.1) What are 3 strengths you have heard discussed when it comes to working with patients with intellectual disability?
    - (5.2) What are 3 challenged you have heard discussed when it comes to working with patients with intellectual disability?
    - (5.3) Is there anything else about your experience providing care to patient with intellectual disability that I haven't asked about that you would like to share? If so, please do.
    - (5.4) Do you have any questions for me at this time?

APPENDIX I: FOCUS GROUP DEBRIEF



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Postfocus Group Debrief

1) Is there anything you were not able to share in the focus groups (either due to lack of time of comfortability) that you wish to share now? ______________________________

2) Please describe at least two key "take-aways" from the focus group. ______________________________

3) As part of the verification process we would like to reach out to focus group participants via email and share our preliminary findings. Would you be willing to provide feedback to ensure the findings from today's focus group accurately capture the voices of focus group participants?

○ Yes, please provide an email address we can reach you at ______
○ No

APPENDIX J: PARTICIPANT DEMOGRAPHIC INFORMATION

Clinic Location	Profession	% of Day Providing DPC (M)	Age (M)	Gender	Years in Current Position (M)	Total Years in Healthcare (M)
Clinic A		50 - 100% (62.5)	25 – 58 (34.13)		.5 - 32 (7.11)	.5 - 35 (9.23)
	D.O. (2)			Female (4)		
	M.D. (10)			Male (11)		
	Mental Health (2)			Prefer not to say (1)		
	Other (2)					
Clinic B		50 - 90% (70.5)	29 - 63 (41)		.25 - 5.5 (2.38)	2.5 - 20 (10.83)
	M.D. (1)			Female (5)		
	Mental Health (4)			Male (1)		
	M.A. (1)			Prefer not to say (0)		
Clinic C		76 - 90% (85.33)	27 - 39 (30.75)		.5 - 1 (.63)	2 – 12 (6)
	M.A. (4)			Female (4)		
				Male (0)		
				Prefer not to say (0)		
Total Sample		50 - 100% (88.05)	25 – 63 (35.19)		.25 - 32 (4.93)	.5 – 35 (9.1)
	D.O. (2)			Female (13)		
	M.D. (11)			Male (12)		
	Mental Health (6)			Prefer not to say (1)		
	M.A. (5)					
	Other (2)					

Note. DPC = direct patient care.

Missing Data: Clinic A = 16 out of 17 focus group participants represented above. Clinic B = 6 out of 24 focus group participants represented above. Clinic C = 4 out of 5 focus group participants represented above

APPENDIX K: COPYRIGHT PERMISSION

From: Maggie Nygren <mnygren@aaidd.org>
Sent: Friday, February 25, 2022, 1:41 PM
To: Shogren, Karrie <shogren@ku.edu>
Subject: RE: Figure Permission

Karrie,

AAIDD grants permission at no cost for Emily Cooper Tucker to include the figure in her dissertation, which may be added to the University of Kansas online database of student dissertations, with the proviso that the figure is cited/attributed as shown below.

I suggest that she hang onto this email as evidence of permission, The permission is explicitly for this purpose only and does not extend to future or derivative works.

Maggie

Margaret A. Nygren, EdD
Executive Director & CEO
American Association on Intellectual and Developmental Disabilities (AAIDD)
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fax: 202-387-2193
www.aaidd.org
Facebook, LinkedIn, Twitter, Bookstore, YouTube
@MaggieNygren1

Thanks for the correction on the name of the university. This email serves to substitute Eastern Carolina University for University of Kansas in the permission granted below.

Maggie