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INCREASING SOCIAL INCLUSION FOR CHILDREN WITH DISABILITIES IN FAITH-BASED SETTINGS: A FOUR-PART DISSERTATION

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INCREASING SOCIAL INCLUSION FOR CHILDREN WITH DISABILITIES IN FAITH-BASED SETTINGS: A FOUR-PART DISSERTATION

DISSERTATION

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Health Sciences
at the University of Kentucky

By

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Lexington, Kentucky

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2022

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ABSTRACT OF DISSERTATION

INCREASING SOCIAL INCLUSION FOR CHILDREN WITH DISABILITIES IN FAITH-BASED SETTINGS: A FOUR-PART DISSERTATION

The aim of this dissertation is to increase the body of research in occupational therapy about how to increase the social inclusion of children with disabilities in faith-based settings. Even since the advent of important legislation like the Americans with Disabilities Act, which paved the way for community participation for individuals with disabilities, individuals with disabilities continue to face barriers to participating in society. Decreased inclusion for individuals with disabilities is seen throughout all sectors of society. One area of regular societal participation for many Americans is in faith-based settings such as churches, synagogues and temples. It has been reported that even in institutions of faith, individuals, including children with disabilities, face barriers to social inclusion. These barriers range from physical and contextual barriers to attitudinal barriers. Faith participation has been deemed important as it can translate into higher quality of life and can be a place of support for individuals with disabilities and their families. While "community participation" and "values, beliefs and spirituality" all fall within the domain of occupational therapy, exclusion in faith-based settings for individuals with disabilities is an occupational injustice that has largely been unaddressed in the occupational therapy literature.

This dissertation is an amalgamation of research projects centered around the primary aim of increasing social inclusion for children with disabilities in faith-based settings. This dissertation includes a systematic review, a scoping review, a phenomenological study and an intervention study. The systematic review examined what supports individuals with disabilities needed to participate in faith-based settings. This review found that individuals with disabilities needed a variety of supports in order to better participate in faith-based settings. No-cost and low-cost supports (such as a welcoming attitude) that faith-based institutions can implement to support the participation of people with disabilities are discussed. A scoping review was conducted to better understand occupational therapy literature about coaching adults to facilitate the participation of children with disabilities. The results of this study helped to shape the definition and coaching protocol used for the intervention study of this dissertation. The phenomenological study looked at the experiences of faith-based volunteers who worked with children with disabilities in their faith settings. This study found that faith-based volunteers wanted more support in serving children with disabilities, they felt called to serve children with disabilities in their faith settings, but also had differing ideas on what participation for individuals with disabilities looks like in faith settings. Finally, the culminating intervention study is described in which occupational performance coaching- a coaching approach for adults to support children with disabilities that is discussed in detail in the scoping review- is used with volunteers who work with children with disabilities in faith-based settings. This study found that an occupational performance coaching intervention provided by an occupational therapist with faith-based children's volunteers was effective at increasing the social inclusion of children with disabilities.

These studies reveal the need for more research to be conducted in the area of faith-based social inclusion for individuals with disabilities. Furthermore, the culminating study in this dissertation (chapter 6) provides implications for occupational therapists to use occupational performance coaching with other community-based volunteers with the broader goal of increasing societal inclusion for individuals with disabilities throughout all facets of society. Other future implications for occupational therapy practice and research are also discussed.

KEYWORDS: Social Inclusion, Inclusion, Disabilities, Religion and Spirituality, Occupational Therapy

Valerie Pearl Miller

01/24/2022

Date

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DEDICATION

To my community, I’m so incredibly grateful for all of you. To team Miller- Richard and Adelaide- thank you for giving me the motivation, love, endless support, patience and words of encouragement to keep going when I didn’t have faith in myself. Richard you are my pillar and Adelaide you are my inspiration. I truly could not have been successful without you two (and your countless trips to the zoo and the museum together). To my parents, Ron and Georgina, who constantly and selflessly help however they can. To my amazing friends and family who have showed up in countless other ways over and over again. Finally, to Jeffrey Foster, my “partner in crime” and the reason I became an Occupational Therapist. This dissertation may be my work but absolutely none of it would have been possible without each of you and your support.

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CHAPTER 1. INTRODUCTION

It is well documented that individuals with disabilities continually face limitations to inclusion in our society (Abbott & McConkey, 2006; Asselt et al., 2015; Centers for Disease Control and Prevention, 2020; Verdonschot et al., 2009). These limitations persist throughout all facets of society including: “(1) domestic life; (2) interpersonal life; (3) major life areas consisting of education and employment; and (4) community, civic and social life” (Verdonschot et al., 2009, p. 55). Social exclusion in all levels of society occurs for children with disabilities as well (Frazee, 2003; Koller et al., 2018; Koller & Stoddart, 2021; Tavares, 2011). Furthermore, when children with disabilities experience social exclusion, often their family as a whole experiences social exclusion too (Amado et al., 2012; Carter et al., 2016). Social exclusion has proven to have deleterious effects on children with disabilities and their families (Amado et al., 2012; National Council of Social Service, 2017; Simplican et al., 2015; Van Bergen et al., 2018).

One area of social inclusion in which children with disabilities experience barriers is within faith-based settings (Ault et al., 2013b; Carter et al., 2016; Poston & Turnbull, 2004; Sullivan & Aramini, 2019). Children with disabilities experience decreased social inclusion in faith settings due to the difficulties they encounter when compared to their same-aged peers, not due to a lack of a desire to participate (Ault et al., 2013; Poston & Turnbull, 2004). Such difficulties include behavioral concerns, communication barriers and negative attitudes and stigma from others in the congregation which limit children with disabilities participation (Sullivan & Aramini, 2019). Decreased social inclusion in faith-based settings continues to negatively impact families and their children with a disability (Carter & Boehm, 2019; Carter et al., 2016).

1.1 Social Inclusion

Social inclusion is a construct that has proven difficult to characterize and there has yet to be a consensus in the literature for how to define it (Cobigo et al., 2012; Koller et al., 2018; Simplican et al., 2015). Similar constructs and terms that are present in the literature include participation (World Health Organization [WHO], 2002), inclusion, and belonging (Carter, 2016). Researchers have tried to conflate many of these terms with social inclusion but it is unclear at this time if these terms can truly be combined or if they are different constructs, due to the variety of ways they are defined and used. In the International Classification of Functioning, Disability and Health, WHO (2002) defines the term participation as “the involvement in a life situation” (WHO, 2002, p. 10). This definition was also adopted by the American Occupational Therapy Association’s (2020) Occupational Therapy Practice Framework 4th edition. The term “inclusion” as it relates to individuals with disabilities has emerged since the deinstitutionalization movement in the 1970’s (Parmenter, 2014). The deinstitutionalization movement occurred when it was recognized that individuals with disabilities (such as cognitive and behavioral disabilities) should not be institutionalized simply for having a disability (Parmenter, 2014). However, as with other terms, “inclusion” lacks a unified definition as well. The United States government has defined inclusion as “a state of being valued, respected and supported. It’s about focusing on the needs of every individual and ensuring the right conditions are in place for each person to achieve his or her full potential” (US Department of Housing and Urban Development, n.d., par.2). Similarly, Carter (2016) used the term “belonging” to communicate the construct of what it means to be part of a group. Carter’s framework of belonging includes multiple facets: being physically present within a group, being invited to be part of that group, being welcomed in the group, being known and accepted within the group, being supported and cared for in the group, being befriended within the group, being needed and loved by the group (Carter, 2016). Although the terms participation, inclusion, and belongingness appear to be related to social inclusion, more needs to be done to examine each construct.

Major limitations with the lack of a unified definition of social inclusion, and even the current definitions described above, is that they remain very expansive and abstract, and thus difficult to measure and research. Therefore, a conceptual definition for social inclusion is imperative to advance social inclusion research. The framework of social inclusion, as described by Simplican et al., (2015) is used throughout this dissertation. Simplican et al. defined social inclusion as “the interaction between two major life domains: interpersonal relationships and community participation” (Simplican et al., 2015, p. 1). This working definition allows for a more concrete concept with which to move forward with social inclusion research. Chapter 4 of this dissertation will go into more detail on this construct and how this researcher is proposing to measure and provide interventions for social inclusion.

1.2 Theoretical Underpinnings

The major theoretical underpinning of this research is occupational justice as described by the Occupational Therapy Practice Framework 4th edition (AOTA, 2020). The lens of the Social Model of Disability (Shakespeare, 2006) is also used in the culminating study in guiding the intervention approach of a coaching model.

1.2.1 Occupational Justice

As the guiding document for occupational therapy practice in the United States, the Occupational Therapy Practice Framework 4th edition (AOTA, 2020) describes the importance of occupational therapists promoting occupational justice. Occupational justice is defined as “a justice that recognizes occupational rights to inclusive participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class or other differences” (Nilsson & Townsend, 2010, p. 58). Occupational therapists are called to help individuals overcome occupational injustices in their lives through various interventions. These interventions can be targeted at the person, activity (or occupation), or the context within which activities occur. There is a recognition in occupational therapy that participation in life’s occupations results in purpose, meaning, health and higher quality of life and should be maintained as desired by the person (AOTA, 2020). Therefore, since children with disabilities continue to face barriers to participating in faith-based settings, it is within the purview for occupational therapists to discover ways to help overcome these occupational injustices.

1.2.2 The Social Model of Disability

Whereas the OTPF-4th ed. (2020) focuses on interventions provided to a person, activity, or context to promote participation, the social model of disability differs. The social model of disability posits that barriers to an individual’s participation in life experiences are not due to the individual’s own disability or limitations but rather are due to social construction (Shakespeare, 2006). Therefore, within the social model of disability, the focus is taken off “fixing” the individual with a disability and rather focuses on “fixing” the context or activity in which an individual with disability participates – removing barriers to allowing participation within that context. The social model of disability still recognizes individuals' impairments but sees them more as a form of diversity instead of a limitation (Shakespeare, 2006). Simply put, in the social model of disability, the disability lies not within the person, but within the physical, societal, attitudinal, political and economical contexts within which a person exists (Bach, 2017; Goering, 2015). When compared to the OTPF-4th ed. instead of looking at how to intervene at the person, context or activity level, the social model of disability looks to intervene at the contextual or activity levels only.

Researchers have demonstrated that historically the focus of social inclusion interventions have been directed towards "fixing" the child with a disability (Gibson et al., 2009; Koller & Stoddart, 2021) which aligns with a more medical model of disability. Examples of the targets of these interventions include: social skills training, video modeling, emotional regulation training, and behavioral shaping for the individual with a disability (Koller & Stoddart, 2021). Rarely do the interventions to promote social inclusion target aspects beyond the individual with a disability towards the environment or activities in which they participate (Koller & Stoddart, 2021). When looking at ways to enact societal change to increase social inclusion for individuals with disabilities, using the social model of disability can be helpful in identifying barriers to promote social inclusion.

Because this dissertation is focused on supporting social inclusion in a broader context beyond the individual level, the social model of disability has helped to guide the understanding of disability and therefore the interventions that are proposed within this dissertation. The focus of this dissertation is not on "fixing" the children with disability, rather it is focused on equipping and supporting others in order to modify the contextual and activity factors better allowing individuals with disabilities to be supported in faith-based settings. While the researcher recognizes that interventions provided at the individual level continue to be important for promoting independence for individuals with disabilities, they are disproportionately used to promote social inclusion (Koller & Stoddart, 2021). Thus, it is recommended that researchers begin to investigate the societal circumstances, external to the individual with a disability, that can facilitate social inclusion as a compliment to standard therapeutic practices.

The primary motivation for this dissertation is to contribute to the body of literature in supporting children with disabilities to be more socially included in faith-based settings. Within faith-based settings, children, and subsequently their families, experience decreased social inclusion due to the barriers that they continually face such as negative attitudes, stigma and contextual barriers (Ault et al., 2013b, Poston & Turnbull, 2004). Historically faith participation has been an occupation largely unaddressed by the field of occupational therapy even though it is a valued part of many peoples' lives (Kessler Foundation and National Organization on Disability, 2010).

1.3 Purpose Statement

The purpose of this research is to contribute to the body of knowledge for occupational therapists on how they can facilitate increased social inclusion in faith-based settings for children with disabilities.

1.4 Study Designs and Research Questions

This dissertation highlights research and results from four studies: one systematic review, one scoping review and two research studies with the overall aim of finding ways for occupational therapy practitioners to support the social inclusion of children with disabilities in faith-based settings. Each of the studies and reviews in this dissertation used the methodology that best suited the research question(s) or interests of that study or review, therefore multiple different methodologies were used.

1.4.1 Study One: A Systematic Review of Supports for Participation in Faith Settings for Individuals with Disabilities

Study one (chapter two) titled “A Systematic Review of Supports for Participation in Faith Settings for Individuals with Disabilities” (completed under the supervision of Dr. Camille Skubik-Peplaski) examined the literature regarding supports that individuals with disabilities stated they need in order to participate in faith-based settings. A total of five studies with a combined sample size of 1,012 participants with disabilities were critically appraised to better understand the supports that individuals with disabilities need to participate in faith-based settings.

This review provides not only occupational therapists, but others interested in increasing the participation of those with disabilities in faith-based settings with practical steps and interventions to put into place. The results of this review are important to the field of occupational therapy because it is a starting point to highlight the supports needed – as verbalized by individuals with disabilities – to participate in faith-based settings. Furthermore, the findings from this systematic review helped shape the direction of this dissertation and the subsequent studies.

1.4.2 Study Two: The Use of Coaching to Support Children with Disabilities in Occupational Therapy: A Scoping Review

Study two (chapter three), titled “The Use of Coaching to Support Children with Disabilities in Occupational Therapy: A Scoping Review” was completed under the supervision of Dr. Dana Howell. Using the PRISMA Guidelines for conducting scoping reviews, a scoping review was completed to better understand how coaching is used in the field of occupational therapy specifically to support the participation of children with disabilities. A total of nine articles were included in this review to gain a better understanding of how researchers define and then conduct coaching protocols with adults for the purpose of increasing the participation of children with disabilities in various contexts.

The purpose of this scoping review was to (1) identify the definitions of coaching used in the field of occupational therapy with adults to support the participation of children with disabilities, (2) outline the key components needed for different coaching practices, (3) identify the format used for coaching to help develop a coaching protocol, and then (4) to understand how coaching interventions are assessed for effectiveness. This scoping review was the basis for how the coaching protocol for study four was created and thus was invaluable to the development of study four’s methods of this dissertation.

1.4.3 Study Three: Understanding the Experiences of Faith-Based Volunteers Serving Children with Disabilities in their Faith Settings

Study three (chapter five) titled “Understanding the Experiences of Faith-Based Volunteers Serving Children with Disabilities in their Faith Settings” was conducted with the assistance of graduate students. This study used a qualitative phenomenological design with eight adult participants who volunteered in their children's programming in their place of faith. The purpose of this study was to better understand the experience of volunteers serving children with disabilities in the children's programming of their faith setting. This study helped the primary researcher to better understand the experience of these individuals in order to learn ways to support them in serving children with disabilities in their settings.

Findings from this study suggested that volunteers wanted more support when serving children with disabilities in their place of faith, they felt called to support children with disabilities and there were differing ideas on what inclusion may look like in faith-based settings for children with disabilities. The subthemes that came out of this study outlined practical steps to support volunteers who serve children with disabilities in faith-based settings such as providing trainings, changes to the environment, wanting to help families and children with disabilities to have a "normalized" experience, and others. The results from this study were used to help guide the development and execution of the culminating study, study four of this dissertation.

1.4.4 Study Four: The Effectiveness of an Occupational Performance Coaching Intervention for Volunteers to Support the Social Inclusion of Children with Disabilities in Faith Settings

Study four (chapter six) titled "The Effectiveness of an Occupational Performance Coaching Intervention for Volunteers to Support the Social Inclusion of Children with Disabilities in Faith Settings" used a concurrent-convergent mixed methods approach utilizing social network analysis and measures of participation with one classroom in the children's programming of a church that consisted of both children with and without disabilities. The primary aim of this study was to determine the effectiveness of a coaching program with the volunteer leaders of that classroom with the goal to increase the social inclusion of children with disabilities.

Findings of this study suggested that utilizing an occupational performance coaching program with community volunteers was both a feasible and effective way to increase the social inclusion of children with disabilities in faith-based settings. Additionally this study demonstrated positive changes beyond the immediate participants of the study with regards to supports the faith setting implemented indicating possible positive attitudinal shifts. Implications for occupational therapy practice are discussed in chapter six.

1.5 Dissertation Overview

Chapters two-through-six provide the basis for understanding for an occupational therapist to support the social inclusion of children with disabilities in faith-based settings as well as providing insight into how a coaching model can be used with community-based volunteers. These chapters have been organized to show multiple perspectives on ways to increase social inclusion for children with disabilities, including researching the literature for supports for participation for individuals with disabilities in faith settings (chapter two) and gathering information from volunteers who serve children with disabilities in their faith settings (chapter five). Chapters three and four provide the background, theoretical basis and rationales of the methods that were used for the culminating study (chapter six) of this dissertation. The last chapter, chapter seven, is a synthesis chapter with a specific focus on what the contents of this dissertation means for occupational therapy practitioners, faith-based volunteers, and children with disabilities and their families. This final chapter also includes future directions of research and areas of investigation to continue this line of inquiry.

1.6 Researcher Statement

The studies and reviews in this dissertation were completed to fulfill the requirements of the PhD program in Rehabilitation Sciences at the University of Kentucky. This research is a culmination of my life experiences and research interests. As a pediatric occupational therapist, I completed a year-long Leadership Education in Neurodevelopmental and related Disabilities (LEND) program at Cincinnati Children's Hospital Medical Center in 2017 with a strong emphasis on community inclusion for children with disabilities. During the LEND program, I helped start a project which has continued with the Cincinnati Zoo on ways to make the zoo more supportive for children with disabilities and their families. Through that project I developed a knowledge of the role and importance of social inclusion not only for children with disabilities but for their families and the employees of the zoo as well.

I have also been involved in American Christian churches for most of my life. My husband has been on pastoral staff of churches in the past and we have been a part of the leadership and we have helped start two new churches. I have observed, on many occasions, children with disabilities being excluded from the children's programming within church settings because the volunteers felt unequipped or uncomfortable serving these children, or simply did not think children with disabilities should be included. I was overwhelmed to realize that individuals and families who may have a child with a disability experienced barriers to participating in their faith, possibly at a time in their lives when they needed more social support, simply because their child with a disability was not welcomed by their congregation. A friend’s son was diagnosed with autism in 2017 and I saw firsthand the impact of the child’s disability on the family’s participation in faith activities. I started training church volunteers at our church and then led a few invited talks on ways to support children with disabilities in other venues. I found, however, that there was limited evidence to support interventions aimed at increasing the social inclusion of children with disabilities specifically in faith-based settings. Furthermore, there was nothing in the occupational therapy literature on the topic at the time. The dearth of information in this area, my experiences with the LEND Program, as well as my background as a pediatric occupational therapist and growing up and being familiar with the American Christian church has guided my current research. One of the limitations of researching anything within faith settings is that they can be difficult to access as an “outsider” but because of my unique life experiences I was well situated to access the population needed for these studies.

My aspiration is that this research can be used in the future as a basis for developing coaching programs to support social inclusion, both within and outside of faith-based settings with the overall goal to increase social inclusion for children with disabilities and their families throughout society.

1.7 Operational Definitions

Disability: “A physical or mental impairment that substantially limits one or more life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (Americans with Disabilities Act of 1990, § 12102). For the purposes of this dissertation, all types of disability including developmental and intellectual disabilities, which are sometimes differentiated from the broader term, will be described as “disability”.

Developmental Disability: “Developmental disabilities (DD) are severe, lifelong disabilities attributable to mental and/or physical impairments, manifested before the age of 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities” (Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000, PL 106-402)

Faith-Based Settings: Any non-profit organization that is centered around religiously held beliefs.

Intellectual Disability: “Intellectual Disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18” (Schalock et al., 2010, p. 8).

Social Inclusion: There are many different definitions for inclusion, community inclusion, social inclusion and participation. For the purposes of this dissertation, Simplican et al.’s (2015) definition of social inclusion will be used. Social inclusion is defined as “the interaction between two major life domains: interpersonal relationships and community participation” (Simplican et al., 2015, p. 1).

CHAPTER 2. A SYSTEMATIC REVIEW OF SUPPORTS FOR PARTICIPATION IN FAITH SETTINGS FOR INDIVIDUALS WITH DISABILITIES

For individuals with disabilities, community participation is considered an important indication of positive health outcomes and overall rehabilitation (Chang, et al., 2013). Those with disabilities often experience decreased community participation due to a variety of barriers which can result in decreased quality of life, mental health, overall health, and social outcomes (Amado et al., 2013; Chang, et. al., 2013). According to the American Occupational Therapy Association (AOTA), "all people, regardless of abilities, should have access to, choice of, and an opportunity to participate in a full range of community activities" (P. 1, Ideishi et al., 2013). According to AOTA's Occupational Therapy Practice Framework (2020) community participation is defined as "engaging in activities that result in successful interaction at the community level (e.g., neighborhood, organization, workplace, school, religious or spiritual group)" (p. 34).

Additionally, the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) lists the importance of considering "community, social, and civic life" when looking at activities and participation of an individual when considering the overall impact of disability (p. 16, 2001). The ICF encourages examination of barriers and facilitators to participation when looking at the environmental impacts on disability (World Health Organization, 2001). In a world where individuals with disabilities are increasingly able to be physically included in different settings, the focus has transitioned to social inclusion as well (Amado et. al., 2013). For individuals with intellectual and developmental disabilities, physical inclusivity is often not the main barrier to participate in community settings (Amado et. al., 2013). The United Nations Convention on the Rights of Persons with Disabilities states that social inclusion or participation is a right and an obligation for society (United Nations, 2006).

One area of regular and ongoing community participation for a majority of people in the United States is within faith settings (Kessler Foundation, 2010). According to Boswell et al., (2007), participating in faith traditions can provide individuals with disabilities with purpose and meaning, connections with their community, a place to express creativity, and a place to experience acceptance. Minton and Dodder reported that individuals with disabilities express a desire to participate in religious activities (2003). However, it is well documented that people with disabilities and their families participate less in faith-based settings, this is due to a variety of barriers (Kessler Foundation and National Organization on Disability, 2010; Poston and Turnbull, 2004). Barriers identified in the literature are physical and psychosocial in nature. Attitudinal barriers, a lack of understanding, acceptance, and support have been noted in various studies (Ault et al., 2013a; Ault et al., 2013b; Carter et al., 2016). Many position statements, professional opinion papers, and studies which use religious leaders and congregants as participants call for the need to increase inclusion for those with disabilities in faith settings (Carter, 2016; Collins & Ault, 2010; Collins et al., 2001; Goldstein & Ault, 2015; McGee, 2010; Poston & Turnbull, 2004; Richie, 2015, Slocum, 2016). However, only recently has research included the perspectives of those with disabilities or family members of people with disabilities in identifying supports for participating in faith settings. There is a mantra from the disability community when discussing disability policy and research that says “nothing about us, without us” that encourages those enacting change to include voices from the disability community (Scotch, 2009).

Therefore, the aim of this systematic review is to examine supports to participation in faith settings as identified by those with disabilities or their caregivers and families. The question that guided this review is: For people with disabilities or their families, (Population), what supports increased participation (Intervention) in faith-based settings (Context)?

2.1 Method

A systematic literature review was conducted as outlined in the following sections. It was conducted by two experienced occupational therapists, one with a PhD and one PhD student. The two researchers conducted the review independently and then compared results until a consensus was reached regarding the inclusion of articles and analysis following the four-step processes of Gough, Oliver, and Thomas (2012). This four-step approach included a systematic search, a screening of the literature, appraisal of literature and data extraction and synthesis.

2.1.1 Systematic Search.

The systematic search stage began by accessing the following online journals: The American Journal of Occupational Therapy (all volumes) and the databases EBSCOhost, Cochrane Reviews and PubMed using the specific search engines: Academic Search Complete, CINAHL/CINAHL Full Text, ERIC, Health Source, MEDLINE Psychology and Behavioral Sciences Collection, and Psych Info. This comprehensive search included all of the previously listed databases which have been known to contain information regarding disability research. Searches from the date of inception till present time of all the databases were utilized. The only limits utilized were for articles to be peer-reviewed to ensure rigor, and articles written in the English language. Various interchangeable terms were utilized to identify “inclusion” and “participation” as well as various terms to encapsulate any sort of faith participation. For the purposes of this study, research discussing all types and denominations of faith-participation were considered. Boolean phrases and the use of an asterisk with roots of words assisted with expanding the search. The following search terms were utilized:

Disabilit* OR Develop* Disabilit*

AND

Inclus* support* OR inclusi* OR participate* OR integration

AND

Church OR religio* OR faith OR Worship OR congregation

NOT: school, education, employ*

A hand search was also completed with relevant articles to identify any further studies that were not identified through the online searches. The following inclusion and exclusion criteria were applied:

- Inclusion: All types of disability
- Exclusion: Articles that did not specifically include people with disabilities or their caregivers as research participants, community participation outside of church/religious participation, expert opinion, and unpublished dissertations.

2.1.2 Screening of the Literature.

After the comprehensive literature search, a screening process was utilized to pare down the relevant information (See Figure 2.1 for the PRISMA flow diagram). A total of 441 references were identified through EBSCOhost using the various search engines. No additional references were identified through PubMed, Cochrane Reviews, the American Journal of Occupational Therapy, or through hand searches. Of those articles identified, 357 were excluded based on title and/or abstract of the article due to not being relevant to this systematic review. Eighty-four full-text articles were then accessed to see if the study met eligibility criteria, of which 79 did not. Of those that did not meet eligibility criteria, 21 were expert opinions, essays or literature reviews, 54 were deemed to be not relevant based on further inspection as they did not relate to the topic of interest, and four were excluded because the subjects did not include those with disabilities or caregivers of individuals with disabilities. A total of five research articles therefore met inclusion criteria and were reviewed, see Table 2.1.

2.1.3 Appraisal of Included Studies.

The appraisal for each study included in this review was based on the Mixed Methods Appraisal Tool (MMAT). This tool allows studies that are qualitative, quantitative or mixed-methods in nature to be compared based on methodological quality (Pluye et al., 2011). See Table 2.2 for the application of the MMAT for the studies

Figure 2.1 PRISMA Flowchart of Study Selection

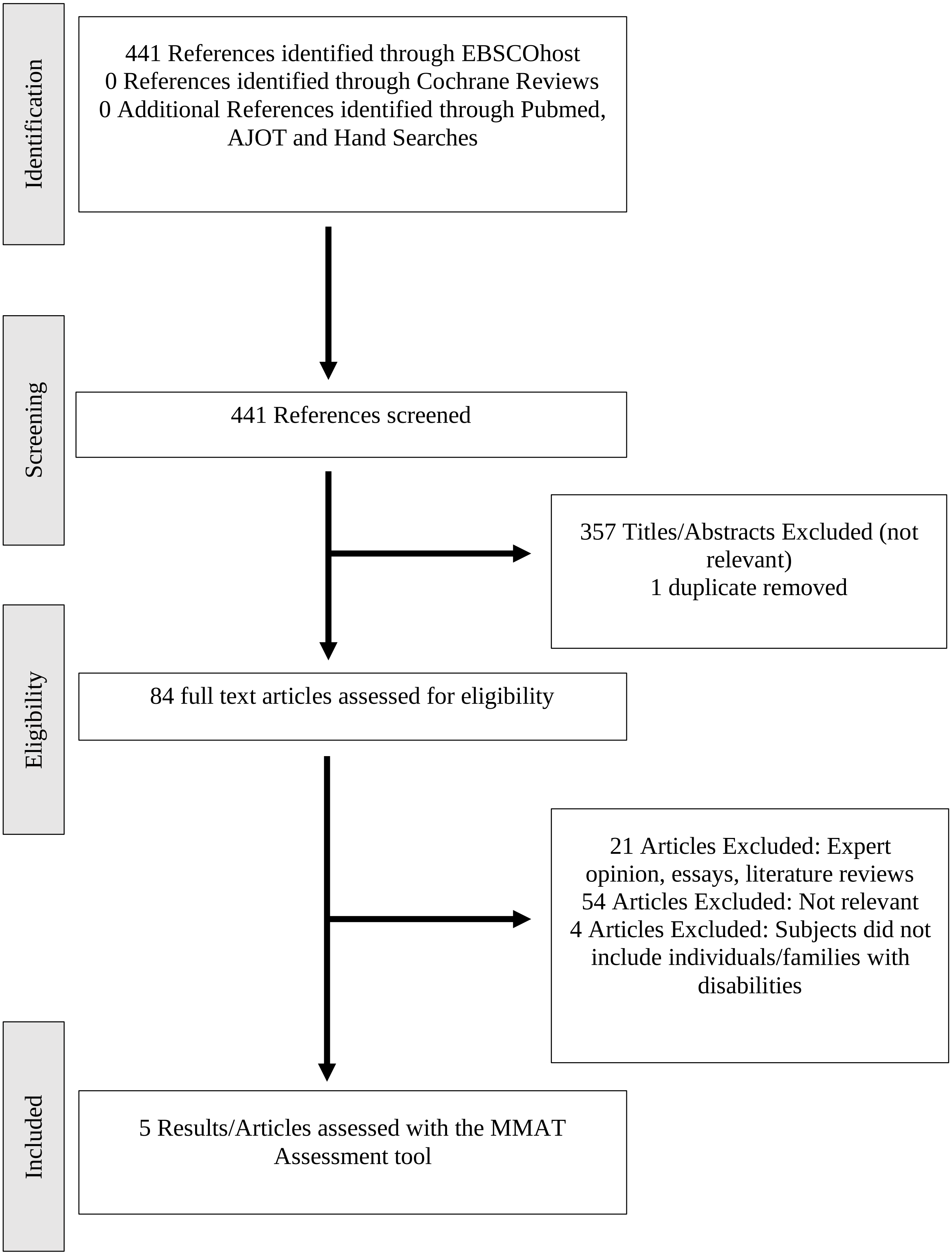


Table 2.1: Articles Included in the Review

Study Design/ Methodology of Articles	**Level of Evidence**	**Number Located**	**Authors (Year)**
Qualitative- Semi-structured interviews	5	1	Hobbs, Bonham, & Fogo (2016)
Quantitative- Close-ended survey	5	3	Ault, Collins & Carter (2013a) Griffin, Kane, Taylor, Francis & Hodapp (2012) Carter, Boehm, Annandale & Taylor, (2016)
Qualitative- Open-ended survey	5	1	Ault, Collins & Carter (2013b)

included in this review. All studies were included regardless of methodological quality for this review. A percentage of MMAT criteria met was utilized to objectively compare study quality across methodological domains.

All of the studies reviewed included clear objectives of the study and utilized data collection that sufficiently answered the research questions. For the qualitative studies included, both studies utilized sources and data analyses that were relevant to address the research questions

The MMAT is comprised of four questions and is meant to be a tool to compare qualitative, quantitative and mixed-methods studies. The questions, while they assist with analyzing the quality of a research study, are limited and not comprehensive for any one

Table 2.2: Mixed Methods Appraisal Tool Applied to the Research Studies

MMAT Criteria	
Types of mixed methods study components or primary studies	Methodological Quality Criteria (MMAT Question #)
Screening Questions	1. Are there clear qualitative and quantitative research questions/objectives, or a clear mixed methods question? 2. Do the collected data allow address the research question/objective?
1. Qualitative	1.1 Are the sources of qualitative data relevant to address the research question/objective? 1.2 Is the process for analyzing qualitative data relevant to address the research question/objective? 1.3 Is appropriate consideration given to how findings relate to the context? 1.4 Is appropriate consideration given to how findings relate the researchers' influence?
2. Quantitative randomized controlled trials	2.1 Is there a clear description of the randomization? 2.2 Is there a clear description of the allocation concealment? 2.3 Are there complete outcome data? 2.4 Is there low withdrawal/dropout?
3. Quantitative non-randomized	3.1 Are participants recruited in a way that minimizes selection bias? 3.2 Are measurements appropriate regarding the exposure/intervention and outcomes? 3.3 In the groups being compared, are the participants comparable, or do researchers take into account the differences between these groups? 3.4 Are there complete outcome data, and, when applicable, an acceptable response rate, or an acceptable follow-up rate for cohort studies?
4. Quantitative descriptive	4.1 Is the sampling strategy relevant to address the quantitative research question? 4.2 Is the sample representative of the population under study? 4.3 Are measurements appropriate? 4.4 Is there an acceptable response rate?
5. Mixed Methods	5.1 Is the mixed methods research design relevant to address the qualitative and quantitative research questions, or the qualitative and quantitative aspects of the mixed methods question? 5.2 Is the integration of qualitative and quantitative data relevant to address the research question? 5.3 Is appropriate consideration given to the limitations associated with this integration in a triangulation design?

	Table 2.2 Continued Responses and Comments				
MMAT Item #	Carter, Boehm, Annandale & Taylor (2016)	Ault, Collins & Carter (2013)a	Ault, Collins & Carter (2013)b	Griffin, Kane, Taylor, Francis & Hodapp (2012)	Hobbs, Bonham & Fogo (2016)
1	Yes- Clear questions were provided on p. 374	Yes- Clear research questions were provided on p. 50	Yes- Clear questions were provided on p. 189-90	Yes- A clear purpose for this study was outlined on p. 384. The overall goal was to "describe characteristics that correlated with greater inclusion for people with disabilities in faith communities"	Yes- Clear research purpose is disclosed on p. 36
2	Yes- the survey instruments directly addressed the research questions.	Yes- the close-ended survey questions allowed for the research questions to be answered	Yes- the open-ended questions on the survey allowed for the research questions to be answered.	Yes- The research design does provide information to answer the research question.	Yes- the phenomenological approach allowed for this research question to be answered.
1.1			Yes- the participants were caregivers or parents of individuals with disabilities who had some engagement (current or previous) with a faith community.		Yes- The participants were individuals with disabilities, however, the authors used purposive sampling and two of the subjects were personally known by the first author, additionally, two of the subjects came from the same congregation, which has decreased diversity among subjects. Additionally, no information is given as to how many individuals were screened to participate prior to choosing subjects.
1.2			Yes- The method of data collection is made clear—through open-ended response boxes parents		Yes- Individual semi-structured interviews were conducted over a period of 2-3 sessions. The author used a

Table 2.2 Continued

MMAT Item #	Responses and Comments				
	Carter, Boehm, Annandale & Taylor (2016)	Ault, Collins & Carter (2013)a	Ault, Collins & Carter (2013)b	Griffin, Kane, Taylor, Francis & Hodapp (2012)	Hobbs, Bonham & Fogo (2016)
			filled out as part of a larger survey. The data analysis process was described in detail and is deemed sufficient to answer the research question.		voice recording to record and then transcribed interviews which were then validated by the research subjects. The author outlines his data analysis steps in detail on pp. 38-9.
1.3			Yes- the authors note in the limitations section that the way that the data was collected (open-ended survey) instead of in-person interaction may have limited the richness of the data that was collected.		Not Sure- The author does not disclose the location of interviews, who else may have been present during interviews or other details about the context. The author does however disclose that it is a limitation that the subjects were from the same community, and two of the subjects attended the same congregation.
1.4			No- The authors do not explain their role, background or credentials except for the author that was provided as the contact for the article. Thus, the authors do not discuss how their background influences the interpretation of the results. There is one note in the data analysis section		Yes- The author discloses that he personally knew two of the subjects as a limitation to the study. Additionally, the author discloses his familiarity with faith settings at the beginning of the article and listing it again in the limitations sections as a potential source of bias. Lastly the author discloses that this research

Table 2.2 Continued

MMAT Item #	Responses and Comments				
	Carter, Boehm, Annandale & Taylor (2016)	Ault, Collins & Carter (2013)a	Ault, Collins & Carter (2013)b	Griffin, Kane, Taylor, Francis & Hodapp (2012)	Hobbs, Bonham & Fogo (2016)
			about the use of a reflective journal kept by the first author to ensure validity of interpretation of the results.		was completed as part of a dissertation.
4.1	Can't Tell- the authors used a large network of disability-based community agencies to help identify potential participants which resulted in a large sample size. However, no power analysis or justification for sample size provided.	Can't Tell- the authors did not state how they obtained their sample of 416 respondents across the United States for their study.		No- the authors used a variety of ways to send survey invitations to potential respondents. The sample size (N=160) was small compared to other survey studies of this type. The majority of the population were Caucasian demonstrating decreased diversity among respondents. There was no justification for sample size obtained.	
4.2	Yes- the authors used a large sample size N=433 to address the research question. Furthermore, the sample included people from a large variety of faith traditions, ages, and demographics as demonstrated on Table 1.	No- While the authors received a large sample size from 35 states in the US, there is a lack of diversity among religious backgrounds identified. Additionally, the author did not collect demographic data on the participants to determine if it was a representative sample.		No- this study failed to get a variety of participants that was representative of a larger population. The population included in the study was mostly Caucasian, mostly college level educated or higher, and mostly affiliated with Christian religions.	
4.3	Yes- Descriptive statistics were utilized to represent results. Variables that were	Yes- survey was created using a mix of items from various other studies of faith participation. The survey		Can't tell- the instrument utilized is clearly described. The survey was developed with input from the "researchers,	

	Table 2.2 Continued Responses and Comments				
MMAT Item #	Carter, Boehm, Annandale & Taylor (2016)	Ault, Collins & Carter (2013)a	Ault, Collins & Carter (2013)b	Griffin, Kane, Taylor, Francis & Hodapp (2012)	Hobbs, Bonham & Fogo (2016)
	measured were clearly defined in the article.	questions were adequate to answer the research question with descriptive statistics utilized for data collection.		members of faith communities, disability advocates and family members of people with disabilities" (p.385). However, it is unclear if the survey was pilot tested or validated prior to the study. It appears that, based on questions provided in the article that the measure does reflect the intended purpose to answer the research question however.	
4.4	Yes- The researchers mailed a total of 545 packets with survey instruments and received 483 back, resulting in an 88% response rate. Due to incomplete packets, or not meeting eligibility criteria, 50 responses were dropped, resulting in an 79% total inclusion rate for responses.	Can't Tell- It is unclear how many families were contacted to participate in the study, only the number of participants is reported. Unable to determine what response rate occurred.		Can't tell- the sampling method is unclear and the authors do not supply information regarding how many invitations were sent out compared to number of responses received.	
% of criteria met	3/4 = 75%	1/4 = 25%	3/4 = 75%	0/4 = 0%	3/4 = 75%

type of methodology. The researchers included the analysis table in Table 2.2 to narratively highlight some of the strengths and weaknesses of each study following the MMAT criteria to provide a more comprehensive analysis of the studies. The translational science of increasing inclusion for those with disabilities in faith settings is in its infancy and thus all peer-reviewed literature has been deemed valuable for this systematic review.

2.1.4 Data Extraction and Synthesis.

Information regarding the study design, population, respondents and a summary of results were extracted by these independent authors from each included article and are detailed in Table 2.3. The five studies were manually analyzed to determine what supports the respondents listed as being helpful for participation in faith settings for people with disabilities. The results were then compared across studies to identify common supports. The supports were compared between the two researchers until consensus was met to ensure agreement of themes. All supports were then listed in a table and the frequency of a given support were totaled. This information can be found in Figure 2.

2.2 Results

The total study sample (n = 1,012) from all of the articles that were reviewed included 945 respondents that identified as having a disability or being the caregiver of a person with a disability. The Griffin et. al. article (2012) was the only study included that also had respondents that were not individuals or caregivers of an individual with a disability. In this study, the rest of the respondents (n = 67, or 47% of study participants

Table 2.3: Article Summary Table

Authors	Title	Journal/ Year	Study Design (n=sample size)	Population	Respondents	Results: Supports That Were Rated as Helpful	MMAT Criteria Met

Ault, Collins, Carter	Congregational participation and supports for children and adults with disabilities: Parent perceptions	*Intellectual and Developmental Disabilities* 2013a	Quantitative - close-ended survey (N=416)	Families of Children with Developmental Disabilities	Parents and Caregivers of a child with a developmental disability	Top rated helpful supports included:
						-welcoming attitude towards those with disabilities (91.5%)
						-support to participate in regular activities (67.3%)
						  -supports for inclusion such as specific programs
						  -education for volunteers/staff
						  -accepting/flexible attitudes
						  -respite/child care for children during services
						  -segregated programs
						  -physical accessibly or rooms to take children who may be having a difficult time
						-parent support groups (48.1%)
						-accessible facilities (46.3%)
							25%

Ault, Collins, Carter	Factors associated with participation in faith communities	*Journal of Religion, Disability and Health* 2013b	Qualitative open-ended survey (N=416)	Families of Children with Developmental Disabilities	Parents and Caregivers of a child with a developmental disability	-Accommodations and adaptations to increase inclusion based on the individuals needs -Communities that take ownership to include those with disabilities	75%

	for individuals with developmental disabilities and their families					-Strong leaders who advocate for inclusion for individuals with disabilities -Parental support during and outside of worship services Additionally, the authors found that the age of the child and the size of the congregation impacted participation for the family. In general it was found that younger children were easier to include compared to older children, and larger congregations tended to have more supports for families compared to smaller congregations.	
Carter, Boehm, Annandale, Taylor	Supporting congregational inclusion for children and youth with disabilities and their families	*Exceptional Children* 2016	Quantitative close-ended survey (N=433)	Families of children and youth with disabilities	Parents and caregivers of a child, youth, young adult with a disability	-Top-rated supports were for the parents instead of directly to/for the child. Top 5 rated supports were: -support groups for parents -congregation-wide disability awareness efforts -resource center -advocates to work with families -respite care -Physical accessibility least-helpful rated support -44% of survey respondents indicated that their current congregation offered none of the 14 listed supports.	75%

						-Larger congregations tended to have more of the supports listed available compared to smaller congregations. -The more supports a congregation offered, the more they were perceived to be committed to the inclusion of people with IDD.	
Griffin, Kane, Taylor, Francis, Hodapp	Characteristics of Inclusive Faith Communities: A preliminary survey of inclusive practices in the united states	*Journal of Applied Research in Intellectual Disabilities* 2012	Quantitative close-ended survey (N=160)	Individuals with disabilities	Parents/ Caregivers with disabilities, individuals with disabilities, leaders in faith communities and participants of faith communities.	-leaders committed to inclusion -welcoming to those with disabilities -roles for people with disabilities to fulfill -physical accessibility -use of educational resources to increase inclusion -positive portrayal of people with disabilities -commitment to social justice -positive relationships with community disability organizations	0%
Hobbs, Bonham, Fogo	Individuals with disabilities: Critical factors that facilitate integration in Christian	*Journal of Rehabilitation* 2016	Qualitative semi-structured interviews (N=3)	Adults with various disabilities (blindness, orthopedic impairment, spinal cord injury)	Adults with disabilities directly interviewed	-Physical accommodations -Emotional and social support from the congregation -Acceptance as a contributor to the congregation -Understanding by other congregation members	75%

	religious communities						

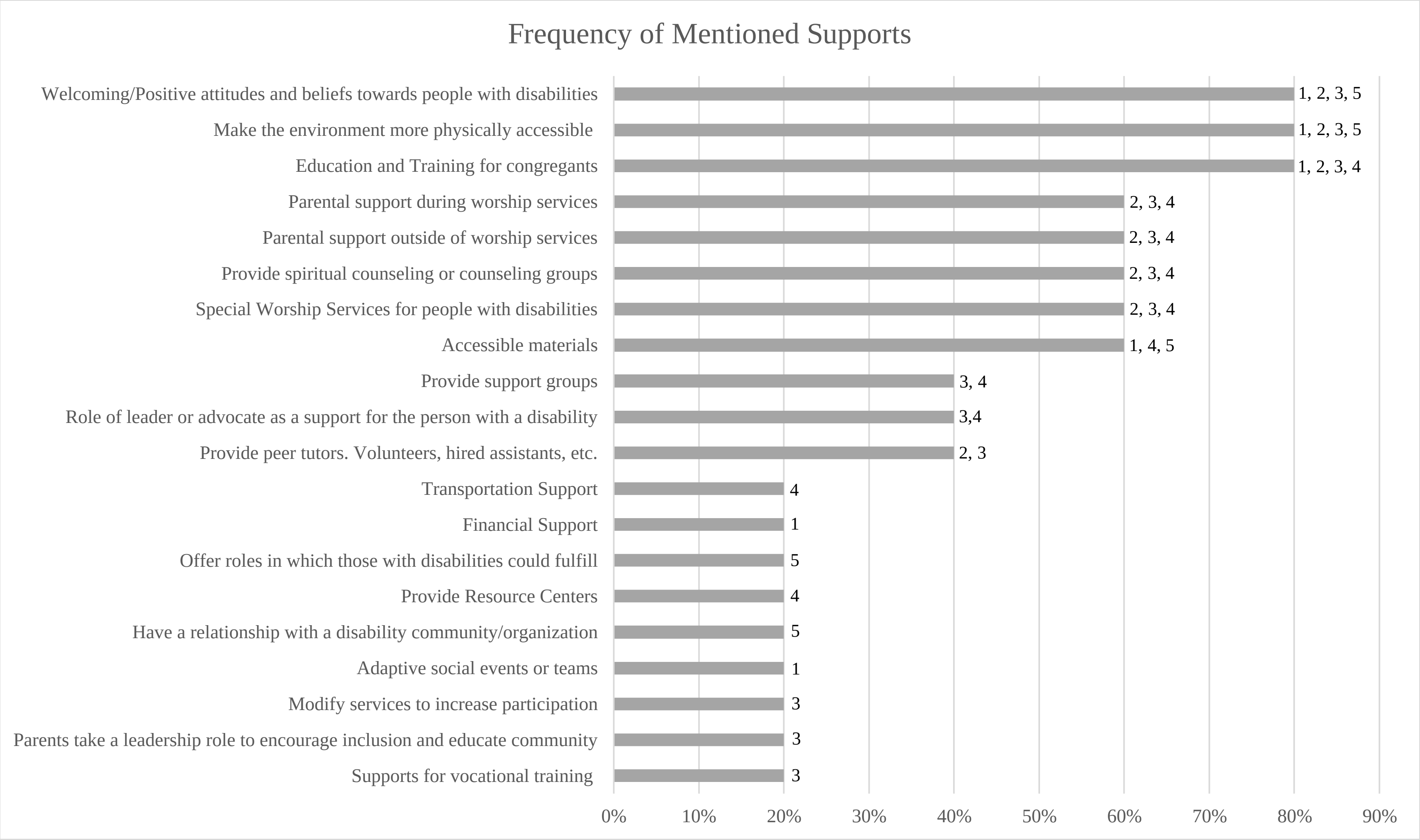


Figure 2: Frequency of Supports Mentioned Key-1: Hobbs et al., (2016), 2: Ault et. al., (2013a), 3: Ault et. al., (2013b), 4: Carter et. al. (2016), 5: Griffin et. al. (2012)

were leaders from various faith communities such as pastors or other lay leaders. All of the studies included respondents that identified from various faith traditions (e.g. Buddhism, Judaism, Mormon, Quaker) but the majority of respondents were from Christian faith backgrounds, including Catholic and Protestant traditions. The participants from all of the included studies were largely individuals or families of individuals with an intellectual or developmental disability (n=1,261, 93%). Other identified disabilities included in the articles were: traumatic brain injury (n=20, 1.4%), orthopedic impairment (n= 17, 1.2%), emotional or behavioral conditions (n=42, 3.1%), and significant health impairment (n=16, 1.1%).

Ault, et. al. 2013b used a qualitative, open-ended response survey while the other studies utilized quantitative close-ended surveys (Ault, et. al. 2013a, Carter et. al. 2016, Griffin et. al. 2012). The Hobbs et. al. (2016) article utilized individual interviews for data collection. All of the studies were conducted within the United States and were published between 2012-2016.

For further analysis, the findings were then categorized by the researchers into two groups—physical accommodations and social-emotional accommodations (Table 2.4). The further classification of the supports can be used for translational change for congregations as practical ways to increase participation for people with disabilities in their congregations. Often, the discussion of inclusion for those with disabilities centers around physical accessibility of the facilities. Faith-based institutions are currently exempt from the Americans with Disabilities Act (1990) which means they are not required to follow physical accessibility guidelines contributing to barriers for individuals with physical disabilities. Additionally, congregations may reside in historic buildings

Table 2.4: Categorized Supports

Physical Accommodations	Social Emotional Accommodations
Physical Environment - Make environment more accessible - Transportation Support - Supports for vocational training - Accessible materials *Social Environment* - Parental support during worship services - Parental support outside of worship services - Special worship services for people with disabilities - Parents take leadership role to encourage inclusion and educate community - Modify services to increase participation - Provide peer tutors, volunteers, hired assistants - Adaptive social events or teams	- Education/Training on disability, behavior and inclusion - Spiritual leaders knowledgeable and inclusive that role model to the congregation - Provide support groups - Offer roles for the disabled participants to fulfill - Provide resource centers - Have a relationship with a disability organization - Provide spiritual counseling - Welcoming/positive attitudes and beliefs towards people with disabilities and their families

where options for making physical accommodations may not be feasible or may be too costly. The researchers wanted to highlight that improving physical accessibility of a faith-setting is only one of the various supports mentioned in the literature. Likewise, there are many supports that have been mentioned in the literature that include low-to-no cost for people with disabilities. All of the supports to participation mentioned were extracted from the results of the included articles. See Figure 2.2 for a chart that displays the frequency of supports mentioned in the literature.

2.3 Discussion

The top three supports mentioned throughout the articles were physical accessibility, welcoming and positive attitudes, and education and training for congregants. These three supports were equally mentioned in four out of the five assessed articles as helpful for increasing participation for individuals with disabilities. While physical accessibility isn’t always a problem for individuals with intellectual and developmental disabilities, the top mentioned supports are very applicable in assisting participation for individuals with intellectual and developmental disabilities.

Other supports mentioned in three of the five articles include: parental support during worship services, parental support outside of worship services, spiritual counseling or counseling groups, specialized worship services for individuals with disabilities and accessible materials. All of these aforementioned supports were listed by individuals and families of individuals with intellectual and developmental disabilities as helpful to increase their participation. Supports mentioned in two out of the five included articles included: support groups, the role of a leader or advocate within the congregation to support the person with a disability and providing volunteers, peers or tutors to assist people with disabilities. Other supports mentioned in only one of the reviewed articles include: providing transportation support, providing financial support, offer roles within the congregation that an individual with a disability could fulfill, provide resource centers, have a relationship with a disability community or organization, provide modified services, provide supports for vocational training, encourage parents of individuals with disabilities to take a leadership role to educate the community, and provide adaptive social events or teams.

The supports mentioned in all of the articles were further broken down into physical and social-emotional supports by the researchers to assist with application. Some supports such as positive and welcoming attitudes and providing specific roles which individuals with disabilities can participate in, are of little-to-no cost to a congregation and could be very practical first steps for a congregation wanting to increase participation for those with intellectual and developmental disabilities. Additionally, one of the supports listed, having an identified leader or advocate within the congregation, could help families and other leaders in the church to bridge the gap of needs that individuals with disabilities and their families may have.

While physical accessibility was a top mentioned support, it was not the only support mentioned in a majority (4/5) of the articles. One of the themes that reoccurred throughout most of the articles was the theme of congregations having positive and welcoming attitudes towards people with disabilities (Ault et. al., 2013a; Ault, et. al., 2013b; Griffin et. al., 2012; Hobbs et al, 2016). This highlights the importance of attitudinal shifts that still need to occur within our society to support participation for people with disabilities. Attitudinal barriers as a limitation to participation in society for those with intellectual and developmental disabilities has been well documented (Anaby et al., 2013; Centers for Disease Control and Prevention, 2020; Law et al., 2007; Rimmer and Rowland, 2008). According to the results of this systematic review, it is understood that these attitudinal barriers that people with disabilities experience in society, also occurs within faith environments. Changing thoughts and attitudes towards people with disabilities often occurs through education and relationship, both of which could be of little-to-no cost to a faith institution as well.

Three-out-of-five articles included both the need for parental supports during and outside of worship services (Ault et. al., 2013a; Ault, et. al., 2013b; Carter et. al). A majority of parents (55.3%) polled in Ault et. al., reported being expected to stay with their child with an intellectual or developmental disability during worship services instead of allowing the child to attend the children's programming without the parent, thus impeding the parents' own faith participation as well (2013b). Parents and caregivers of children with developmental disabilities are at a higher risk of marital dysfunction, mental illness, and caregiver burnout (McConnell & Savage, 2015; Weiss, 2002). These risks can be exacerbated by isolation due to decreased participation in valued community activities, such as faith settings. Therefore, providing supports like respite or other assistance outside of the weekly worship services may have positive implications for the families and caregivers of individuals with a disability. Other inexpensive actions that can be taken include: spiritual counseling, specialized worship services, accessible materials, providing support groups, having a disability advocate in the community, providing peer tutors, establishing relationships with disability organizations, and providing resources to members.

One surprising finding in the Carter et. al. article was that there was a large discrepancy between the amount of supports rated by parents as being helpful and the amount of supports actually offered at the respondents' respective congregations (2016). This further highlights that individuals with disabilities and their families are not receiving enough support within their faith setting to participate to the extent of which they desire. Ault et. al. reported that almost one third (32.3%) of parents of individuals with disabilities have changed their places of worship due to their child not being supported or welcomed. Almost half (46.6%) of parents surveyed had limited their own participation in a religious activity directly due to their child not being supported (2013a). Additionally, Carter et. al. found a positive link between the amount of supports offered within a congregation and the amount and duration of time that a family attends that congregation.

The implications for this systematic review are two-fold. The first implication is to demonstrate that research on community inclusion, and more specifically religious participation, for individuals with disabilities from the perspective of those with disabilities is in its infancy and further studies need to be completed to support this population. Secondly, this study describes important supports that faith congregations can put into place to increase participation for individuals with disabilities and their families.

Often disability inclusion is thought in terms of costly physical accommodations that may not be feasible or affordable for congregations. These researchers wanted to highlight that physical inclusion, which may include costly renovations, is only one support listed in the literature to increase participation for those with disabilities. Furthermore, these researchers found that many supports mentioned by individuals with disabilities and their caregivers or families included low-cost options which congregations could begin adopting more readily than some of the more expensive supports that were mentioned.

The supports were divided between “physical accommodations” and “social emotional accommodations”. The physical accommodations included supports or changes to the physical environment as well as social environment and these supports tended to be costlier. Whereas the social emotional accommodations included low-to-no-cost supports such as congregations having a welcoming/positive attitude towards people with disabilities, having leaders who are knowledgeable about various disabilities and who act as role models to support inclusion, and offering roles within the congregation that those with disabilities could fulfill. These supports to participation could easily be adopted into any congregation or community setting. The list found in Table 3 can further provide practical, evidence-based supports for those who want to promote participation for those with disabilities in their congregation.

2.3.1 Limitations

There are limitations to this study, beginning with the design of the studies chosen which have limited strength of evidence due to their survey design. While the author conducted a comprehensive search of the literature, only five articles were found that addressed this topic explicitly from the perspectives of people with disabilities or their caregivers. Thus, all studies found were included, regardless of level of evidence or quality to begin assisting congregations in ways to be more inclusive. Another limitation of this study is that it is difficult to compare results across studies. The authors tried to facilitate comparison by doing a comprehensive frequency count (Figure 2) of supports that were mentioned throughout all of the articles. Several supports were combined such as respite care which was included under “parental supports outside of worship services.” However, even with the frequency distribution provided, it is difficult to compare results across studies due to the various study designs and how results were reported. For example, even though most parents reported physical accessibility would be a top support for their congregation to have overall, it was listed between “not at all helpful” or only “a little helpful” for their family across studies since the majority of the respondents did not have an orthopedic impairment. Thus, the wide variation of needs for individuals with disabilities necessitates that these are broad suggestions, not specific to any one disability or condition, which may be seen as a limitation to this study.

Another limitation of this study is the concern for validity within studies. Many of the studies utilized instruments that were created by the researchers and not validated in populations prior to their respective studies. Thus, the tools that the authors utilized could have been biased, or could have missed valuable information. Additionally, with one of the qualitative studies (Hobbs et al., 2016), the actual format of the questions were not included, thus there could have been a leading question bias with the interview questions. Additionally, unpublished research articles and dissertations were not included in this systematic review which may have resulted in relevant research findings being omitted. Yet, the authors made every attempt to control for each limitation with their final goal to ultimately increase family participation in faith settings.

2.4 Conclusion

This is the first systematic review conducted on identifying specific supports to increase participation for individuals with disabilities in faith communities. The most frequent actions a group can make to increase participation for all members in faith-based settings are:

- Offer welcoming/positive attitudes towards all members
- Make the environment more accessible
- Provide education and training to members
- Offer parental support during worship services
- Equip parents with support outside of worship services

- Provide spiritual counseling
- Host special worship services for people with special needs
- Make available accessible materials
- Provide support groups
- Create the role of an advocate to support individuals with special needs
- Come up with peer tutors, volunteers or hire assistants

Despite the limitations, this systematic review provides valuable information and insights into specific supports that congregations can provide to increase participation for individuals with disabilities. The World Health Organization's ICF model encourages clinicians to consider barriers and supports to participating in activities such as community life (2001). Until recently, participation in religious settings for individuals with disabilities has not been studied, yet remains an important part of most peoples' lives. Participation in religious communities can have a positive impact on one's physical and mental health (George et al., 2002). Future research should include more rigorous and generalizable studies so that individuals with intellectual and developmental disabilities can participate to the extent that they desire in congregations. Future studies should focus on evaluating the effectiveness of listed supports on increasing participation for individuals with disabilities in faith settings. Future research could also examine the impact of increasing participation in faith settings on satisfaction and quality of life measures for individuals with disabilities.

CHAPTER 3. THE USE OF ADULT COACHING TO SUPPORT CHILDREN WITH DISABILITIES IN OCCUPATIONAL THERAPY: A SCOPING REVIEW

Coaching, at its most basic connotation, is partnering with someone in a way that increases their skills. Coaching is a collaborative process, versus a one-time or limited training or skill demonstration (Miller-Kuhanek & Watling, 2018; Ziegler & Hadders-Algra, 2020). The concept of coaching first appeared in the mid-19th century (International Coaching Federation, n.d.) and the term was largely used only in the sports arena until the mid-20th century (Morrison, 2010). Coaching to support growth, either professionally or personally, has become increasingly prevalent since the 1960's (Kessler & Graham, 2015; Morrison, 2010).

Coaching has been a well-established practice in the education sector for several decades (Yoon et al., 2007). Researchers have demonstrated that coaching provided to educators significantly improves the use of evidence-based practices implemented by the teachers, increases the likelihood of behavior change by the coached teachers, and increases professional learning (Bethune & Wood, 2013; Kretlow & Bartholomew, 2010; Wei et al., 2009; Yoon et al., 2007). Studies have also demonstrated the effectiveness of coaching models in the business world as a management tool (Theeboom et al., 2013). Coaching has similarly been used in the field of nursing. According to Olsen et al. (2010), health coaching by nurses with patients has demonstrated effectiveness in a variety of domains such as chronic illness self-management, aging, and instilling healthy behavior changes in the adult and pediatric populations. Thus, coaching is a tool that may be used to improve the skills of others and has been used in a variety of contexts.

One way coaching has been used in the rehabilitation sciences is to support children with disabilities by providing coaching to the adults around them. Occupational therapists are uniquely equipped to provide coaching interventions. Coaching is client- and family-centered; it is occupation-based and focused on supporting the participation of the coachee or, in the case of providing coaching to parents, supporting the participation of the targeted child (Graham et al., 2009). These aforementioned characteristics embody occupational therapy best practices (Graham et al., 2009). Coaching is also considered to be aligned with a family-centered approach in pediatric rehabilitation due to the collaborative nature to support a child's needs and to build family capacity (Adams & Tapia, 2013; Little et al., 2018; Schwellnus et al., 2020; Ward et al., 2020). Additionally, occupational therapists are trained in various contextual theories, such as the Person-Environment-Occupation (PEO) model (Law et al., 1996) which makes them experts in recognizing the many personal and contextual factors that can influence one's participation. Coaching in occupational therapy has largely been used for parents to support the needs of their children with occupational performance problems due to disability (Kessler & Graham, 2015). Coaching is beginning to be used in other ways in occupational therapy, such as coaching those who have had a stroke (Kessler et al., 2017), but the majority of published studies to date, which are reviewed below, are focused on coaching parents of children with disabilities to facilitate participation and occupational performance of the children with disabilities.

There are different models and definitions of coaching present in the literature. One model commonly used in the field of pediatric practice is from Rush and Sheldon's book *The Early Childhood Coaching Handbook* (2011). According to Rush and Sheldon (2011), coaching is "an adult learning strategy in which the coach promotes the coachee's ability to reflect on his or her actions as a means to determine the effectiveness of an action or practice and develop a plan for refinement and use of the action in immediate and future situations” (p. 8). They described five required components to produce desired outcomes with coaching, including: 1) joint planning with the coach and coachee, 2) exploring options through collaboration, 3) practicing new skills, 4) reflecting on performance, and 5) the provision of feedback (Rush & Sheldon, 2011). When providing coaching as an intervention, these key components are considered integral for evidence-based coaching practice in pediatric rehabilitation (Ward et al., 2020). Likewise, Knowles’ theory of andragogy (often referred to as adult learning theory) supports the use of coaching as a learning mechanism with adults because coaching is used in real-life scenarios and uses directed, facilitated questions to support the self-directed learner (Cox, 2015). Dunst and Trivette’s (2012) reviews of adult learning practices found that coaching components such as sharing knowledge, demonstration, opportunities to practice, and reflection and reassessment, were all considered effective learning strategies for adult learners. Thus, coaching is an appropriate occupational therapy intervention for adults to support the participation of children with disabilities.

3.1 Coaching Models Used

There are two typologies of coaching that are unique to occupational therapy: occupation-based coaching and occupational performance coaching. Goal setting, problem solving and a collaborative, strengths-based approach which are part of Rush and Sheldon’s (2011) coaching principles spans both occupation-based coaching and occupational performance coaching. However, there are some distinctions between the two models (Kessler & Graham, 2015).

3.1.1 Occupation-Based Coaching

Occupation-based coaching is largely facilitated by the coached adults with minimal support from a therapist. The coached adults identify the goals, develop and implement the strategies, and evaluate the effectiveness of those strategies in supporting their goals (Little et al., 2018). The role of the therapist is to ask facilitating questions and make reflective comments throughout the process to guide the coachees in their own discovery with little professional input or knowledge sharing from the therapist (Little et al., 2018). Goals with occupation-based coaching are to either improve the parent-child interaction or to support the child's participation. In addition to the traditional coaching principles mentioned above, reasoning through different strategies is part of occupation-based coaching (Little et al., 2018).

3.1.2 Occupational Performance Coaching

Occupational performance coaching involves the coached adults being guided by the therapist in their goal setting and development of strategies to overcome the challenges they are facing (Graham et al., 2009). Occupational performance coaching goals can be focused on a child's performance or on the adult's performance in relation to supporting their child. This is similar to occupation-based coaching but with occupational performance coaching, the adult can be the sole target of a goal. Occupational performance coaching does not focus on improving client-factors such as impaired body structures, but rather focuses on modifying social and environmental barriers to facilitate increased participation (Kessler & Graham, 2015). While both occupation-based coaching and occupational performance coaching use therapist questioning to guide the coached adults in making decisions, occupational performance coaching allows for the therapist to impart more of their professional experience and knowledge in helping the family identify strategies that may achieve their goals (Graham et al., 2009). Additionally, the provision of emotional support from the therapist to the parent is an important component of occupational performance coaching that is not explicitly discussed in occupation-based coaching (Kraversky, 2019). Lastly occupational-performance coaching encourages the use of "joint feedback" with regards to Rush and Sheldon's (2011) feedback criteria- suggesting that parents should also provide feedback to the therapist during coaching sessions (Graham et al., 2009).

3.2 Coaching in Pediatric Occupational Therapy

Several systematic reviews have demonstrated the effectiveness of coaching parents and caregivers to support children with disabilities (Miller-Kuhaneck & Watling, 2018; Schwellnus et al., 2020; Ward et al., 2020; Ziegler & Hadders-Algra, 2020). Currently, coaching parents for supporting children with disabilities is considered a "green light approach" indicating there is enough evidence to consider it a best practice using Novak and Honin's (2019) evidence alert traffic light system. Coaching has also been shown to increase parental efficacy and satisfaction for implementing changes to support their child's participation (Dunn et al., 2012; Foster et al., 2013).

Using a coaching model can be a paradigm shift for both therapists and the coached adults. For some therapists, the behavior changes required to move from a traditional therapy model as a "leader" to a coaching model as a "partner" can be a challenge (Ziegler & Hadders-Algra, 2020). For the parents who have been coached, the coaching model requires more involvement and work on the part of the family instead of passing the therapeutic role to a therapist (Ziegler & Hadders-Algra, 2020). Coaching is a process where therapists guide the coachees to solutions rather than directly telling them what to do, which takes more effort for the coached adult and therapist relationship but does lead to more empowered families (Ziegler & Hadders-Algra, 2020).

Unfortunately coaching as an intervention lacks a unified definition or approach. Ziegler and Hadders-Algra (2020) stated that individuals should be trained in coaching in order to do it appropriately, but did not outline a specific training mechanism for therapists to be trained. At the time of this manuscript being written, there are no published coaching protocols in occupational therapy. The processes and components or key components that go into coaching need to be better defined within the occupational therapy literature in order to increase the fidelity of the intervention approach (Kessler & Graham, 2015; Schwellnus et al., 2020; Ward et al., 2020; Ziegler & Hadders-Algra, 2020). Additionally, the way that outcomes are measured and the format with how coaching occurs lacks unity and clarity within the literature (Schwellnus et al., 2020; Ward et al., 2020).

Other reviews have examined the effectiveness of coaching used in pediatric rehabilitation, but no reviews to date have examined how coaching interventions are being conducted, the ways that coaching is measured, and what key components are reported as being utilized (Schwellnus et al., 2020; Ward et al., 2020). Therefore, the purpose of this scoping review was to examine the use of coaching interventions with adults to support children with disabilities within the field of occupational therapy. More specifically:

- What populations were studied?
- What terms and definitions were used to describe the coaching?

- How were the coaching interventions structured?
- What were the key components of the coaching intervention?
- What assessment tools were used to measure the effectiveness of coaching?
- What were the outcomes of coaching interventions?

3.3 Methods

Because evaluating the strength of evidence for coaching as an intervention was not an objective of this review, a scoping review was selected over a systematic review (Munn et al., 2018). No previously written protocol for this scoping review existed. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses- Extension for Scoping Reviews (PRISMA-ScR) guidelines as published by Tricco et al. (2018) were followed to conduct the review.

3.3.1 Inclusion Criteria

Articles were included if: a) coaching adults as an intervention for supporting children with disabilities or occupational performance problems was the focus of the study, b) the coaching intervention was provided by an occupational therapist, and c) the article examined the outcomes of the coaching intervention (as opposed to parent perceptions of coaching, for example). Articles were excluded if: a) other interventions beside coaching were provided b) the article was not written in English, c) if it was a theoretical paper, review or published research protocol, and d) if the article was not peer-reviewed. Articles from the inception of the databases until present time were considered.

3.3.2 Information Sources

The systematic search was conducted in August 2021 by a single researcher. EBSCOhost database was accessed using the specific search engines: Academic Search Complete, CINAHL with Full Text, ERIC, Health Source - Consumer Edition, MEDLINE, Psychology and Behavioral Sciences Collection, APA PsycInfo, Sociological Collection, and eBook Academic Collection (EBSCOhost). Additionally, the *American Journal of Occupational Therapy* was also accessed and searched.

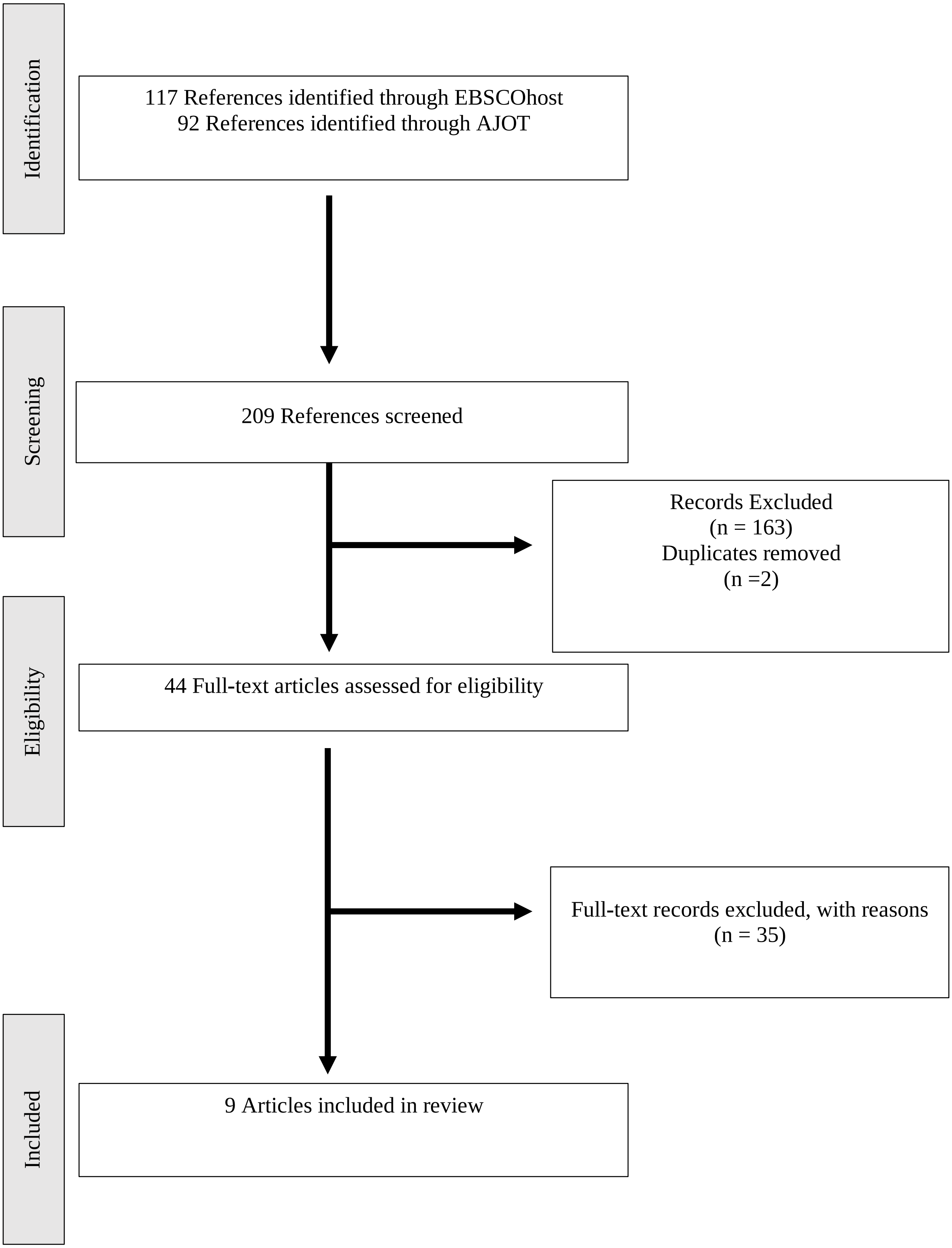
3.3.3 Search Strategy

The following search terms were utilized: Coach* AND Child* with disability* OR Child* with special need* OR disab* child* AND Occupational Therap* OR OT.

3.3.4 Selection of Sources of Evidence

After a comprehensive search of the literature, a screening process was used to pare down relevant articles (see Figure 3.1 for the PRISMA flow diagram). One-hundred and seventeen references were identified through EBSCOhost using the various search engines and 92 additional references were identified through the *American Journal of Occupational Therapy*, for a total of 209 articles. Of those articles identified, 165 were removed due to irrelevancy or being duplicates. Of the reviewed abstracts, 44 articles appeared to meet criteria and the full-text articles were accessed to determine eligibility.

Figure 3.1: PRISMA Flowchart of the Systematic Search



Of the reviewed full-text articles, 31 were excluded because they were not relevant, two were excluded because the participants did not match the scope of this review, one was excluded because it was a study protocol and one was excluded because it was unclear if the coaching was provided to the adults in the study. Thus, a total of 9 articles met inclusion criteria and were reviewed.

3.3.5 Data Reporting Procedures

Following the PRISMA-ScR guidelines, a data charting form was created to systematically extract data from each article to help answer the research questions (see Table 3.1). The categories that were examined from each article to answer the research questions included: the study purpose, the population with which the study was completed, the structure of the coaching (number of sessions, frequency, location, and who participated in the coaching) the key or important components for coaching as described by the authors, the term and definition of coaching used, and the outcome measures that were utilized. Additionally, a category for recording the conclusions of each study was created to help with analysis and further discussion.

3.3.6 Synthesis of Results

A data charting table was created with each column matching one research objective of this review. Data from each article was pulled out of each reviewed study and put in the respective columns of the table. The table was then visually analyzed to find commonalities and differences among the studies within each analysis category. Thematic analysis for each research objective was reviewed and reported.

Table 3.1: Data Charting Form for Coaching Articles Reviewed

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
Anaby et al., (2016)	"To examine the effectiveness of environment-based interventions on participation of youth with physical disabilities" (p.83) with respect to participation in leisure activities	n = 6 Adolescents with physical disabilities aged 14-17 years and their parents	Coaching – a process where the "therapist engages and coaches both parents and adolescents on how to identify and apply effective strategies to improve the child's participation" (p.84)	Total Number of Sessions: 12 Frequency: Weekly Length of Sessions: not documented Format: In-person Location: In the family's home or community Session Participants: Parents and targeted adolescents	1. Review goals 2. Identify and evaluate environment-based barriers/facilitators to participation 3. Explore strategies to modify environmental barriers and/or activity demands 4. Provide knowledge about useful strategies to search for information and advocate for the child's inclusion (p. 84)	Demographic Questionnaire (Initial Baseline) Canadian Occupational Performance Measure (COPM) (Initial baseline, intervention, and follow-up) Participation and Environment Measure for Children and Youth (PEM-CY) (Initial Baseline, Follow-up)	The intervention led to significant improvement in all but one participant's COPM scores and goals. Parents indicated increased satisfaction. Although not statistically significant, the number of activities that the participants participated in increased post-intervention as well.

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
						The KIDSCREEN-27 (Initial Baseline, Follow-up) CSQ-8 (Follow-up)	
Bulkeley et al., (2016)	To "explore the hypothesis that mothers will better manage their children's behavior challenges in the context of daily routines after a family-centered coaching intervention using sensory-based strategies" (p. 5)	n = 3 Parent/child dyads (ages 4-5 years) with autism spectrum disorder (ASD)	Coaching – No definition provided Referenced Dunn et al. (2012) article on coaching	Total Number of Sessions: 4 Frequency: Weekly Length of Sessions: 1 hr Format: In-person Location: In the family's home Session Participants: Parents, unclear if	1. Discussion 2. Reframing of the problem 3. Joint Problem solving	Visual Analog Scale (VAS) (Initial baseline, during intervention, 1-week post-intervention) Infant/Toddler Sensory Profile (Used to determine Eligibility) The Autism Diagnostic Observation Schedule (ADOS)	The coaching intervention showed "promise" for improving the problematic behaviors due to sensory processing problems for the children. However, sustained impact was only noted in 1/3 participants at 1 week follow up-demonstrating

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
				targeted children were part of coaching session		(Used to determine Eligibility)	that the tested dosage may not be enough to sustain long-term behavior changes
Dunn et al., (2012)	To test "an occupational therapy contextual intervention for improving participation in children with autism spectrum disorders and for developing parental competence" (p. 521)	n = 20 Families with children with ASD aged 3-10	"Coaching is an evidence-based intervention method that is family centered and promotes adult learning… occurs in family settings, promotes parent-directed goals and solutions, and builds parents' capacity to identify and implement interventions during life	Total Number of Sessions: 10 Frequency: Weekly to Bi-weekly (occurred over 12-15 weeks) Length of Sessions: 1 hour Format: In-person Location: In the family's home or community	1. Use of reflective statements/ questions to guide parents with problem-solving a. Awareness b. Analysis c. Alternatives d. Action Stated that they followed coaching principles outlined by Rush and Sheldon (2011) but no other specifics mentioned	The Sensory Profile (Pre) The following testing battery was Measured at 4 time points- before, during, after intervention and at follow-up: ○ COPM ○ Goal Attainment Scaling (GAS) ○ Parenting Stress Index- Short	Significant improvements in the child's performance, significant decreases in parental stress and increases in parental efficacy occurred after coaching and were maintained (and even improved) at 4 weeks post-intervention

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
			routines" (p. 520)	based on family's goals Session Participants: Parents, unclear if targeted children were part of the coaching sessions		Form (PSI-SF) ○ Parenting Sense of Competence Scale (PSOC)	
Graham et al., (2010)	To determine: "can OPC [occupational performance coaching] contribute to improvement in the occupational performance of children and parents? And What are parents' experiences of OPC	n = 3 Parent/ Child dyads (ages 5-9) who had concerns about their child's occupational performance	Occupational Performance Coaching – "an enablement-focused, parent-directed intervention designed for use by occupational therapists working with parents of children with performance	Total Number of Sessions: 10 Frequency: Weekly Length of Sessions: 1 hr Format: In-person Location: University-based clinic	1. Emotional Support 2. Information Exchange 3. Structured process a. Set goal b. Explore options c. Plan action d. Carry out plan e. Check performance f. Generalize	COPM (Pre-intervention, Post-intervention) GAS (Post-intervention)	Improvements occurred in both parent and child performances after occupational performance coaching. Additionally families reported improvements in their confidence to try new tasks

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
	intervention?" (p.6)		difficulties" (Graham, et al., 2009 as cited in Graham et al., 2010, p. 4)	Session Participants: Parents, targeted children were invited but mostly did not attend			and reported less stressful interactions with their family overall.
Graham et al., (2013)	To "[examine] the effectiveness of occupational performance coaching in improving children's and parents' occupational performance and parents' self-competence" (p.11)	n = 29 Parents (all mothers) of children aged 5-12 years who had concerns with their child's occupational performance	"Occupational Performance coaching, a strengths-based approach for working with people affected by occupational performance challenges" p.10	Total Number of Sessions: 3-8 depending on the needs of the family (median of 5 sessions) Frequency: Weekly Length of Sessions: approximately 1 hr Format: In-person	1. Emotional Support 2. Information Exchange 3. Structured Process a. Set goal b. Explore options c. Plan action d. Carry out plan e. Check performance f. Generalize 4. Collaborative performance analysis	The Adaptive Behavior Assessment System II-Parent Form (ABAS II) (Pre-waitlist) COPM (Pre-waitlist, Pre-intervention, Post-intervention, Follow-up) GAS (Pre-waitlist, Pre-intervention,	Significant improvements were made in all goals for the mothers and children's performance and were maintained after 6 weeks post-intervention. Improvement in parental self-competence also occurred but was not clinically significant.

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
				Location: University-based clinic Session Participants: Parents, targeted children were invited to the coaching sessions but almost half (46%) did not attend		Post-intervention) PSOC (Pre-waitlist, Pre-intervention, Post-intervention, Follow-up)	Generalization of improvements with tasks that were not addressed in the intervention “may also have occurred” (p.16) indicating that skills learned during coaching may expand beyond targeted tasks.
Little et al., (2018)	“To evaluate the efficacy of occupation-based coaching delivered via telehealth for families of young children with ASD” (p.1) “In terms	n = 18 Families of children with autism spectrum disorder (ASD) up to age 6	“Occupation-Based Coaching is an intervention that combines the principles of coaching with occupation-centered reasoning”	Total Number of Sessions: 12 Frequency: Weekly Length of Sessions: not documented	Structured process: 1. Setting goals 2. Exploring options 3. Planning Action 4. Carrying out the plan 5. Checking performance 6. Generalizing 5 Key Principles:	Demographic Form (Pre-intervention) Sensory Profile 2nd ed. (Pre-intervention)	Occupation-based coaching via telehealth can significantly increase parental efficacy and a child with ASD’s activity participation.

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
	of affecting caregiver competence and child participation" (p.2)		(Graham, et al., 2013 as cited in Little, et al., 2018, p.2)	Format: Telehealth Location: over Zoom video conferencing Session Participants: Parents	1. Authentic contexts 2. Family interests and routines 3. Caregiver interaction and responsiveness 4. Reflection and feedback 5. Joint plans (p.3)	Social Responsiveness Scale – 2nd ed. (Pre-intervention) PSOC (Pre-intervention, Post-intervention) Assessment of Preschool Children's Participation (Pre-intervention, Post-intervention) COPM (Pre-intervention, Post-intervention) GAS	Occupation-based coaching can successfully be delivered via telehealth.

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
						(Post-intervention)	
Pashazadeh Azari et al., (2019)	To test whether a contextual intervention adapted for autism spectrum disorder can "improve occupational performance and parental self-efficacy" (p. 20)	n = 36 total, n=18 in the coaching (intervention) group Parents of children aged 3-10 with ASD	"Occupational Performance Coaching, or simply 'coaching' is an intervention has [sic] recently begun to receive attention in the early intervention literature and is practiced in family-centered programs… [it] enables parents to realize and carry out therapeutic strategies within life routines" (p. 4)	Total Number of Sessions: 2 training group sessions and 10 individual coaching sessions Frequency: Weekly Length of Sessions: 45 minutes Format: In-person Location: In the family's home or community Session Participants: Parents, and	1. Following Adult learning principles 2. Setting shared goals 3. Using a strengths-based approach to support parent's performance 4. Shared problem-solving process with therapist asking reflective questions to guide parents' thinking	Demographic Questionnaire (Pre-intervention) Short Sensory Profile II (Pre-intervention) Gilliam Autism Rating Scale II (Pre-intervention) COPM (Pre-intervention, Post-intervention, 4-week follow-up) GAS (Pre-intervention, Post-	Compared to the control group, the group that received the coaching had meaningful increases in participation of the children, improved COPM scores, GAS scores and parent efficacy. Additionally, the improvements were sustained 4 weeks post-intervention (compared to the control group which did not maintain

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
				targeted children were invited to attend but most did not		intervention, 4-week follow-up) Parenting Sense of Efficacy Measure (PSEM) ((Pre-intervention, Post-intervention, 4-week follow-up)	improvements with the standard level of treatment).
Schwellnus et al., (2020)	"To investigate the impact of a solution-focused coaching intervention designed for pediatric rehabilitation on the attainment of participation goals for children/youth with CP" (p.1)	n = 12 Families with their children and youth (aged 6-19) with Cerebral Palsy	"Solution Focused Coaching (SFC) is a specific form of brief coaching that emphasizes a focus on clients' strengths and supports their generation of unique solutions for their	Protocol was individualized based on the family's needs. Total Number of Sessions: 3-5 Frequency: Weekly or biweekly Length of Sessions:	• Strengths-based • Goal-oriented • Client-centered • Highly collaborative sharing and integration of family expertise with rehabilitation provider's expertise	COPM (Pre-intervention, Post-intervention) GAS (Post-intervention) Qualitative Interviews (Post-intervention)	Participants' scores significantly improved in performance and satisfaction scales of the COPM and in goal attainment within the 3-5 coaching sessions. Additionally, participants noted that the coaching

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
			situation." (p.2)	60-90 minutes Format: In-person Location: In the family's home, community, or a treatment center as decided by the family Session Participants: Parents and targeted children			provided them with a sense of partnership and a sense of empowerment. Additionally, parents noticed that their acquired skills generalized to other activities after the coaching intervention.
Suja Angelin, et al. (2021).	"To assess the effectiveness of OPC in improving occupational performance and parenting competence of mothers of	n = 36, 18 in the intervention group Mothers of children (3-12 years) with Autism	"Occupational Performance Coaching (OPC) focuses specifically on enabling children's and parents'	Total Number of Sessions: 10 Frequency: Weekly	• Emotional support (connect)—acknowledging and resolving parents' intrapersonal challenges; • Information exchange	COPM (Pre-Intervention, Post-intervention, at 4 week follow up)	An Occupational performance coaching intervention caused a significant improvement in the

Article	Study Purpose	Population Studied	Name/ Definition of Coaching	Coaching Structure (Frequency, setting, format)	Key Components for Coaching Listed	Assessment Tools Used (and when)	Conclusions
	children with disabilities in an Indian context" (p.38)	Spectrum Disorder, ADHD, Intellectual Disabilities and Sensory Difficulties	participation in occupations in the home and community through therapist-guided but parent-identified solutions to occupational performance barriers" (p. 39)	Length of Sessions: 45-60 minutes Format: In-person Location: At an occupational therapy center Session Participants: Mothers of the children with disabilities	(share)—using Collaborative Performance Analysis (CPA) by the parent and therapist • Structured process (structure)—a clear sequence of steps that guide the overall direction of interactions	Parenting Sense of Competence Scale (PSOC) (Pre-Intervention, Post-Intervention, at 4-week follow-up) Goal Attainment Scale (GAS) (Pre-Intervention, Post-Intervention)	occupational performance of the child with a disability and the mother, improved the mother's sense of competence and increased overall satisfaction compared to a control group.

3.4 Results

This review sought to better understand how coaching adults as an intervention to support children with disabilities is conducted in the field of occupational therapy. Each research objective is reported separately below.

3.4.1 Populations Studied with Coaching Interventions

The first objective was to understand what populations have been studied using adult coaching as an intervention to support children with disabilities. It was found that younger children with developmental disabilities were the most common. Of the reviewed studies, more than half (Bulkeley et al., 2016; Dunn et al., 2012; Little et al., 2018; Pashazadeh Azari et al., 2019; Suja Angelin et al., 2021) were conducted with families where the targeted child was of younger school-age (ages ranged from 3-12 years) with the developmental disability of autism spectrum disorder. One of the reviewed studies (Anaby et al., 2016) specifically targeted adolescents (aged 14-17 years) with physical disabilities. One of the studies (Schwellnus et al., 2020) targeted a wide range of ages (6-19 years) but was specific to the disability of cerebral palsy. Lastly two studies targeted children ages 5-12 years with "occupational performance problems" but no specific diagnoses were listed (Graham et al., 2010; Graham et al., 2013).

3.4.2 Terms and Definitions Used for Coaching Interventions

The second objective sought to identify the terms and definitions used to describe coaching, in order to determine if there was consistency or consensus among the literature. The terms and definitions, and even use of the same terms, varied among the studies. One article (Bulkeley et al., 2016) used the term "coaching" but did not provide any other information other than referencing the Dunn et al. (2012) article on coaching.

Two other articles (Anaby et al., 2016; Dunn et al., 2012) similarly used the term "coaching" but provided different definitions of what coaching meant. Anaby et al. (2016) defined coaching as a process whereby the "therapist engages and coaches both parents and adolescents on how to identify and apply effective strategies to improve the child's participation (p.84); whereas Dunn et al. (2012) defined coaching as "an evidence-based intervention method that is family centered and promotes adult learning… [it] occurs in the family setting, promotes parent-directed goals and solutions and builds parents' capacity to identify and implement interventions during life routines (p.520). Both definitions by Anaby et al. (2016) and Dunn et al. (2012) focused on increased participation for the targeted individual and included the coaching component of joint planning with the parent but had variations in the full definitions with Dunn's definition being more descriptive.

Four of the nine studies (Graham et al., 2010; Graham et al., 2013; Pashazadeh Azari et al., 2019; Suja Angelin et al., 2021) used the term "occupational performance coaching". All four articles defined occupational performance coaching differently but all had the basic components of family-centered intervention to support the participation of a child. One article (Little et al., 2018) used the term "occupation-based coaching" and defined it as "an intervention that combines the principles of coaching with occupation-centered reasoning" (Graham et al., 2013 as cited in Little et al., 2018, p.2). Graham et al. (2013) in their article describe coaching as "a goal-focused conversational format… used to guide clients to examine their goals in detail and identify changes to the performance context that improve goal achievement (p. 11). Lastly one article (Schwellnus et al., 2020) used the term "solution-focused coaching" and defined it as a "form of brief coaching that emphasizes a focus on clients' strengths and supports their generation of unique solutions for their situation" (Schwellnus et al., 2020, p. 2).

3.4.3 Structure of Coaching Interventions

The third objective sought to understand the structure of coaching interventions that were used within the occupational therapy literature. This included the total number of sessions provided, the frequency with which the coaching occurred, the length of each coaching session, the format of the session, the location of the session and finally who participated in the session. Even though there were no established protocols for coaching in the occupational therapy literature that defined the structure of coaching, there were many similarities across studies.

Every study used weekly or biweekly coaching sessions. For the studies that reported the length of each coaching session, all were one-hour in length except for Pashazadeh Azari et al. (2019), which recorded 45-minute sessions; Suja Anglelin et al. (2021), which varied between 45-60 minutes; and Schwellnus et al. (2020), who recorded sessions lasting between 60-90 minutes. Every study used face-to-face coaching with the exception of Little et al. (2018) which was testing the efficacy of coaching via telehealth.

Five of the reviewed studies conducted the coaching sessions either in the family's home or in their local community depending on the goals of the family. Two studies, both by Graham et al. (2010; 2013), used a university-based clinic as the setting for coaching sessions; Suja Angelin et al. (2021) used an occupational therapy clinic; and Little et al., (2018) used telehealth.

The session participants always included the parents in the coaching. Three studies (Graham et al., 2010; Graham et al., 2013; Pashazadeh Azari et al., 2019) invited the targeted children to the coaching sessions and two studies (Anaby et al., 2016; Schwellnus et al., 2020) required the targeted children to be at the coaching sessions. Two studies (Little et al., 2018; Suja Angelin et al., 2021) did not allow the children to attend the coaching sessions. The other reviewed studies did not make it clear if the targeted children were part of the coaching sessions (Bulkeley et al., 2016; Dunn et al., 2012). It is of note that the two studies that required the targeted children to attend the coaching sessions (Anaby et al., 2016; Schwellnus et al., 2020) were the ones that included older children and adolescents. This may be due to the coaching intervention desiring the child's input more as they aged.

Lastly, the number of sessions from study to study varied, ranging from three (Graham et al., 2013; Schwellnus et al., 2020) to twelve total coaching sessions (Anaby et al., 2016; Little et al., 2018). The most frequently reported number of coaching sessions used was ten (Dunn et al., 2012; Graham et al., 2010; Pashazadeh Azari et al., 2019; Suja Angelin et al., 2021). Two studies were variable and ranged from three- to-eight sessions depending on the needs of the client (Graham et al., 2010; Schwellnus et al., 2020). Only one study limited coaching sessions to four total sessions for all participants (Bulkeley et al., 2016).

3.4.4 Key Components for Coaching

The next objective sought to identify the key components for coaching. Four of the reviewed articles (Dunn et al., 2012; Graham et al., 2010; Graham et al., 2013; Little et al., 2018) clearly followed the guidelines from Rush and Sheldon (2011) for their processes with coaching. The five articles that did not explicitly follow Rush and Sheldon's coaching guidelines still listed the process of joint problem solving as a key component (Anaby et al., 2016; Pashazadeh Azari et al., 2019; Schwellnus et al., 2020; Suja Angelin et al., 2021). Four of those five articles (Anaby et al., 2016; Pashazadeh Azari et al., 2019; Schwellnus et al., 2020; Suja Angelin et al., 2021) additionally mentioned setting joint goals with the family. Bulkeley et al. (2016) was the only reference that did not explicitly describe setting goals with the family. Two of the reviewed articles (Pashazadeh Azari et al., 2019; Schwellnus et al., 2020) explicitly mentioned the use of a strengths-based approach and three of the occupational performance coaching articles (Graham et al., 20210; Graham et al., 2013; Suja Angelin et al., 2021) mentioned the use of emotional support for families, consistent with the occupational performance coaching model.

3.4.5 Outcome Measures Used With Coaching

The next research objective sought to understand what common outcome measures were used to study the effects of coaching. Every study reviewed, except for the Bulkeley et al. (2016) study, used the Canadian Occupational Performance Measure (COPM) as one of their outcome measures. The COPM is a client-centered, occupation-focused outcome measure that assesses a client’s performance and satisfaction on any individually identified areas of occupation (COPM, n.d.). Additionally, a majority (7/9) of the articles used Goal Attainment Scaling (GAS) as an outcome measure (Dunn et al., 2012; Graham et al., 2010; Graham et al., 2013; Little et al., 2018; Pashazadeh Azari et al., 2019; Schwellnus et al., 2020; Suja Angelin et al., 2021). GAS is a standardized approach to measuring progress towards individualized goals (Krasny-Pacini et al., 2016). It consists of creating scaffolded goals to measure a client’s progress towards a targeted outcome.

Five studies used an outcome measure to assess either parental self-competence (Parent Sense of Competence Scale), parental self-efficacy (Parenting Sense of Efficacy Measure), parental stress (Parenting Stress Index) or parental satisfaction (CSQ-8) with regards to the coaching intervention (Dunn et al., 2012; Graham et al., 2013; Little et al., 2018; Pashazadeh Azari et al., 2019; & Suja Angelin et al., 2021). Three studies also included measures to assess their specific topic of interest, such as the Assessment of Preschool Children's Participation or the Participation and Environment Measure for Children and Youth (Anaby et al., 2016; Little et al., 2018; Schwellnus et al., 2020).

3.4.6 Outcomes of Coaching Interventions

Lastly, this review examined the outcomes of coaching adults to support children with disabilities. Every study demonstrated positive results from coaching, similar to findings from other reviews that have been conducted on the effectiveness of coaching within pediatric rehabilitation (Miller-Kuhaneck & Watling, 2018; Schwellnus et al., 2015; Ward et al., 2020; Ziegler & Hadders-Algra, 2020). Seven studies demonstrated significant improvements in clients' COPM scores (Anaby et al., 2016; Dunn et al., 2012; Graham et al. 2010; Graham et al., 2013; Pashazadeh Azari et al., 2019; Schwellnus et al., 2020; & Sunja Angelin et al., 2021). Eight of the studies demonstrated improvements for the parents in terms of parent self-efficacy, parent satisfaction, decreases in parental stress, increased confidence, and feelings of self-competence as well as an increased sense of empowerment (Anaby et al., 2016; Dunn et al., 2012; Graham et al., 2010; Graham et al., 2013; Little et al., 2018; Pashazadeh Azari et al., 2019; Schwellnus et al., 2020; & Suja Angelin et al., 2021). Additionally, of the six studies that completed a follow-up measure (Anaby et al., 2016; Bulkeley et al., 2016; Dunn et al., 2012; Graham et al., 2013; Pashazadeh Azari et al., 2019; & Suja Angelin et al., 2021), only one (Buckleley et al., 2016- the one with the fewest number of coaching sessions) did not demonstrate sustained improvements at follow-up. Two studies noted that the learned skills by the parents were generalized to other tasks in supporting the targeted child (Graham et al., 2013; Schwellnus et al., 2020).

3.5 Discussion

This review sought to better understand the use of adult coaching to facilitate participation of children with disabilities within the occupational therapy literature. It systematically examined nine different articles for commonalities and differences which are detailed above and further discussed here.

3.5.1 Terminology

The most used term for coaching across the reviewed studies was "occupational performance coaching." Occupational performance coaching is more detailed in its process compared to the other aforementioned types, which may increase the fidelity and reliability of the intervention. Additionally, occupational performance coaching is getting increased attention in the field of occupational therapy and has been called the "ultimate facilitator" of function by Kraversky (2019). Occupational performance coaching explicitly follows the well-established principles of coaching as developed by Rush and Sheldon (2011). Occupational Performance Coaching also incorporates occupational therapy principles such as therapeutic use of self through providing emotional support and encouraging mutual information exchange and feedback between the parents and therapist, making it a robust choice for occupational therapists. This review demonstrated that even though there were some commonalities with terms, definitions still differed from study to study, highlighting the need for unified terms and definitions in the field. Until unified terminology, definitions and approaches are determined, further research with higher levels of evidence such as meta-analyses on the effects of coaching will be difficult to measure.

3.5.2 Format

Most studies that used coaching as an intervention completed coaching sessions on a weekly or bi-weekly basis with the most commonly reported number of sessions being ten weekly and lasting an hour each. It is important to note that the study that completed the fewest number of sessions demonstrated positive results, but it did not demonstrate significant results, or outcomes that were measurable at a follow-up assessment. This information needs to be considered as therapists need to ensure they provide enough coaching to make clinically meaningful changes. More research should be conducted however, to determine the most effective and efficient frequency, dosage and model of coaching.

3.5.3 Outcome Measures

Most of the studies used the COPM and GAS as outcome measures. This is likely due to the flexibility of both tools being able to measure individualized constructs and goals in a systematic way. Novak (2014) suggested that rehabilitation therapists use the COPM and GAS to measure coaching interventions. Both measures have good psychometric properties and are able to demonstrate change in performance. The COPM has internal consistency reliability as well as good test-retest reliability, it has been deemed valid, and has good responsiveness to change (COPM, n.d.). A change of 2 points in either category (performance or satisfaction) when re-testing is considered a clinically significant change (COPM, n.d.). GAS is used in many different disciplines and with a wide variety of populations to measure constructs that do not otherwise have a standardized assessment to measure (Krasny-Pacini, et al., 2016). When creating a GAS, the goals should be set with the client, thus content validity of the GAS is high. Furthermore, the joint goal-setting nature of GAS follows many of the reviewed studies processes for coaching interventions. GAS has been shown to have high responsiveness to assessing change with rehabilitation interventions (Krasny-Pacini et al., 2016).

The reviewed studies also used measures to determine how the coaching practices affected parents such as measuring their self-efficacy or levels of stress. It is worth reiterating that all studies in this review demonstrated positive outcomes with a coaching intervention, further supporting the literature that coaching adults to improve the occupational performance of children is an effective intervention strategy in occupational therapy (Miller-Kuhaneck & Watling, 2018). The information compiled in this scoping review about the use of coaching, format, and outcome measures provides a framework to guide therapists who want to conduct coaching interventions. Developing structured protocols for conducting and evaluating coaching interventions may increase the fidelity of this practice.

3.5.4 Future Research

It was noteworthy that most of the literature to date included coaching models provided to families that had younger children, often with autism spectrum disorder. This may be due to researchers that have published most on this topic having a narrow target of their research agendas. Many of the articles in this scoping review were conducted by the same group of researchers, including Dunn, Graham, and Foster. More research needs to be conducted to determine the use and efficacy of a coaching model with families with older children and with other disabilities, such as Anaby et al. (2018), who conducted coaching on older adolescents with physical disabilities, and Schwellnus et al. (2020), whose coaching included children and youth up to age 19 with cerebral palsy.

Further research should examine which key components are critical to ensuring positive outcomes when using a coaching model. All reviewed studies demonstrated positive outcomes even though the key components between the studies differed. Examining whether certain components or combination of components have a stronger impact over others would be pertinent to know when developing a structured coaching protocol. Many, but not all of the reviewed articles included joint problem solving and goal setting as important components. Several of the studies explicitly mentioned providing emotional support as a key component, which aligns with the cornerstone practice of therapeutic use of self as outlined in the Occupational Therapy Practice Framework -4th ed. (AOTA, 2020). However, if an article did not explicitly describe using emotional support, it does not mean emotional support was not provided because therapeutic use of self is considered synonymous with occupational therapy best practice. This key component needs to be examined further to determine whether it needs to be explicitly stated and/or used or not. Similarly, only two reviewed studies (Pashazadeh Azari et al., 2019; Schwellnus et al., 2020) mentioned specifically using a strengths-based approach. Other articles may not have used a strengths-based approach or did not explicitly mention it because a strengths-based approach is also considered good practice in occupational therapy. Finding the right mix of key components to get the most robust outcomes with a coaching protocol is another area of research that would only help to strengthen the use of a coaching intervention in occupational therapy.

3.5.5 Implications for Practice

This review demonstrates that, conducted at the right dosage, coaching is an effective intervention not only improving outcomes for children with disabilities but also adult confidence and sense of self-competence in working with children with disabilities. Additionally, the benefits of coaching appear to continue beyond treatment. More specifically, this review provides a comprehensive understanding of how coaching as an intervention is utilized within occupational therapy and can provide a starting framework for therapists interested in conducting a coaching intervention.

One thing to note about this review – even though the search criteria allowed for studies in which the coached adults were outside of the targeted child's parent, no such studies were found within the occupational therapy literature. When the researcher sought out literature from other disciplines to find studies where the coached adults were those other than parents or teachers to support children with disabilities, only one study appeared. Baggerman et al. (2015) provided coaching, as special educators, to a community volunteer in a faith-based setting to better support a child with a disability. Coaching adults in the community is an unexplored area where occupational therapists can and should use their professional skills to support participation for those with disabilities.

3.5.6 Limitations

One limitation of this study is that it was conducted with a single researcher. In order to increase the rigor and validate the results, it is recommended that another researcher independently conduct the search to extend the findings. Another limitation to this study is that only articles that explicitly used the term coaching were included in the search. There could potentially be more references where terms such as “instruction” or “teaching” were used instead of “coaching” but the principles may have matched those of coaching presented here, and thus may have been included to increase the findings. This adds to the argument that a unified definition needs to exist in the literature to ensure that equivalent comparisons are being made and valid conclusions are occurring in the occupational therapy literature. Lastly a limitation is that this study limited the scope to understanding how coaching adults is used to support children with disabilities. While coaching presented in the occupational therapy literature is mostly used in this population, it is important to understand how it is being used with expanding populations as well.

3.5.7 Conclusions

Coaching is an emerging evidence-based practice in the field of occupational therapy. There lacks consensus on a definition or approach in how to conduct coaching within occupational therapy. This scoping review examined the coaching literature where adults were coached to support children with disabilities. It was found that this model has only been used in parent/child relationships and not with other adult/child relationships which is an area of large potential within the field of occupational therapy. Though there are limitations to this review, this review is the first of its kind that identifies how to conduct coaching based on existing evidence. Future research should seek to discern the ideal dosage of coaching for optimal results. Future research should also focus on expanding coaching to other adults, such as community volunteers and workers, to support children with disabilities in a variety of settings.

CHAPTER 4. USING SOCIAL NETWORK ANALYSIS TO MEASURE SOCIAL INCLUSION FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Individuals with intellectual and developmental disabilities (IDD) experience a variety of barriers to social inclusion in society (Abbott & McConkey, 2006; Asselt et al., 2015; Centers for Disease Control and Prevention, 2020). Historically, inclusion was described as the physical presence of those with disabilities among those without disabilities. However, researchers have begun examining a newer concept called “social inclusion” (Asselt et al., 2015; Novak Amado et al., 2013). Social inclusion is a term that has recently emerged in the literature to encompass an understanding of inclusion within the broader societal context.

Simplican et al. (2015) defined social inclusion specifically for individuals with IDD using an ecological model. Their model proposes that social inclusion occurs throughout various levels of society, with the focus on two major domains- interpersonal relationships and community participation. Thus, the concept of social inclusion goes beyond the physical presence of disability and examines the level of social interaction and participation that one has throughout society (Simplican et al., 2015). At a simplified level, social interaction pertains to the structure, the makeup, and characteristics of relationships (Simplican et al., 2015), and participation is defined as “involvement in a life situation” (World Health Organization, 2002, p.10).

There is a paucity of research in the area of social inclusion for individuals with IDD. The first studies of inclusion emerged after the deinstitutionalization movement of individuals with disabilities in the 1970s and 1980s (Novak Amado et al., 2013). Since then, the majority of studies have examined the role of inclusion only in school-based settings (Idol, 2006; Patton et al., 2006). Much of the literature has focused primarily on the barriers to social inclusion rather than examining facilitators of social inclusion, the effectiveness of interventions to increase social inclusion, or ways to measure social inclusion.

Many have called for the need to increase social inclusion for those with disabilities in society (Abbott & McConkey, 2006; Asselt et al., 2015; Collins & Ault, 2010; Goldstein & Ault, 2015; Poston & Turnbull, 2004). However, without a way to measure social inclusion, it is difficult to assess interventions aimed at increasing social inclusion for individuals with IDD. To date, there are limited options for assessments that measure social inclusion for individuals with IDD, and no assessments that measure both domains of social inclusion as defined by Simplican et al. (2015). The purpose of this paper is to present a way to utilize social network analysis as an innovative way to measure one component of social inclusion- social interaction- of individuals with IDD and to discuss how it can be combined with other measures of participation to assess one's degree of social inclusion.

4.1 Barriers to Social Inclusion for People with IDD

Simplican et al.'s (2015) model purports that social inclusion occurs in all domains of life through participation in community and life activities. Likewise, the World Health Organization's (WHO) model states that social inclusion occurs throughout various domains including domestic life, interpersonal life, major life activities (work, education) and throughout community civic and social life (WHO, 2001). Despite these opportunities for social inclusion throughout society, individuals with IDD face significant barriers, keeping them socially excluded from many facets of society. Asselt et al. (2015) concluded that individuals with IDD have fewer opportunities to participate in community groups. Additionally, individuals with IDD have reported there are limited events or activities in which they are able to participate (Abbott & McConkey, 2006; Asselt et al., 2015). Even when individuals with IDD are able to physically attend activities they often find there is a lack of support to actually participate in those activities, thus leading to them being socially excluded (Abbott & McConkey, 2006; Ault et al., 2013a; Ault et al., 2013b; Simplican et al., 2015).

Furthermore, despite the advent of the Americans with Disabilities Act (ADA) (1990) which, among many things, requires new public buildings to be physically accessible by all, individuals with IDD report that physical barriers continue to negatively impact their ability to be present and thus included in many parts of society (Asselt et al., 2015). Several studies have discovered that a lack of available, valued social roles in which to participate also negatively impacts social inclusion for individuals with IDD (Asselt et al., 2015; Griffin et al., 2012). Lastly, negative attitudes and stigma from community members towards those with IDD continues to be a major limiter of social participation for people with IDD (Abbott & McConkey, 2006; Ault et al., 2013a; Ault et al., 2013b; Carter et al., 2016).

While strides have been made to increase social inclusion, those with disabilities still experience social exclusion. Feeling socially included is an important part of life and belonging, and social exclusion has been shown to have negative outcomes (Amado et al., 2013). Being socially excluded from one’s community has been deemed a social determinant of health by the WHO (n.d.) because of the detrimental effects it can have on quality of life and health status. Social exclusion in individuals with disabilities leads to increased feelings of loneliness and isolation (Amado et al., 2013). Additionally, studies have demonstrated that social exclusion leads to poorer health outcomes (van Bergen et al., 2018) and poorer employment outcomes for individuals with disabilities (Evens & Repper, 2001). Studies have also demonstrated the positive effects of social inclusion for individuals with disabilities in increasing ratings of overall quality of life (National Council of Social Service, 2017). Given the significant role that social inclusion can play in overall health and well-being, it is important to be able to measure social inclusion to develop evidence-based strategies for increasing social inclusion for those with IDD.

4.2 Measuring Social Inclusion

Currently there are limited tools that assess the construct of social inclusion for individuals with IDD. Many of these tools only assess one component of social inclusion; participation or social interaction, but do not address both. For example, the WHO's (2001) International Classification of Function includes assessment tools that measure participation for individuals with IDD in various domains of community participation, but not social interaction. Likewise, person-centered assessments such as Goal Attainment Scaling (GAS) (Kiresuk & Sherman, 1968) or the Canadian Occupational Performance Measure (COPM), (Law et al., 2014) can be used to measure an individual's changes in participation over time, but do not measure social interaction. In a systematic review of participation assessments for individuals with IDD, all of the tools that were identified included some measures of interpersonal relationships based on self-report, yet did not specifically measure degree of social interaction or discuss results in relationship to social inclusion (Chang et al. 2013). These measures included the Activity Card Sort, the Guernsey Community Participation and Leisure Assessment, the Client's Assessment of Strengths, Interests and Goals, the Community Participation

Indicators, the Independent Living Skills Survey, the Katz Adjustment Scale, the Maastricht Social Participation Profile, and the Participation Assessment with Recombined Tools – Objective and the Social Functioning Scale; none of these directly correlated their measures to the construct of social inclusion (Chang et al., 2013).

The Social Inclusion Scale (SIS) is currently viewed as a “gold standard” for measuring social inclusion as it is the only one that directly purports to measure social inclusion. One limitation to this self-reported outcome measure is that it has not been normed on populations with disabilities (Wilson & Secker, 2015). Additionally, while the SIS measures three different dimensions of social interaction, it does not have any true measures of participation. Another self-report tool, the Social Profile, examines the social participation of individuals in a group (Donohue, 2007), but does not provide information about an individual’s degree of interaction or social inclusion. Lastly, a tool for measuring activity participation in children, the Children’s Assessment of Participation and Enjoyment and the Preference of Activities for Children (CAPE-PAC), is a parent report tool but also does not examine the construct of social interaction. Furthermore, the CAPE-PAC is only meant to be used with children (King et al., 2006) and therefore would exclude adults as a measure of social inclusion.

Most of the tools that measure components of social inclusion rely on self-report; however, there are several challenges with using self-reported outcome measures with the IDD population. People with IDD may experience difficulties with the cognitive and language aspects of these assessments, which may yield unreliable results (Fujiura and the RRTC Expert Panel on Health Measurement, 2012). Furthermore, while patient or parent-reported outcome measures do provide helpful information, they are based on perception of the respondent and may not completely capture the reality of what is being measured. More objective measures need to be used to measure social inclusion to determine the effectiveness of interventions. Social network analysis, in conjunction with measures of participation may be a solution to measuring social inclusion.

4.2.1 Social Network Theory

Social network theory was created to analyze and understand relationships and how people interact in groups and organizations (Borgatti et al., 2018), which makes it ideal as a measure of social interaction. Social network theory has a wide variety of applications across business, social, and health science domains. According to social network theory, how people are socially connected to others "determines in part the constraints and opportunities that he or she will encounter, and therefore identifying that position is important for predicting… outcomes such as performance, behavior, or beliefs" (Borgatti et al., 2018, p.1). An individual's position within a social network, as well as the overall structure of their network, can have various implications, both positive and negative. Granovetter (1973) posited that people who serve as "bridges" – for example, an individual who serves as a primary connection between two different groups of people within the network- may hold a lot of power and influence. This person may hold a lot of social capital – meaning they would have many resources through their connections and could control the information between the two groups (Borgatti et al., 2018). Conversely, if an individual is on the edge of a network but is not connected to any others in the network (in social network theory, this is called a "pendant"), they are least likely to demonstrate influence over their network and are the least connected to their network (Borgatti et al., 2018). Thus, understanding one's position within a social network can have various implications on the experiences and opportunities that one may have within that social network.

4.2.2 Social Network Analysis

Social network analysis utilizes concepts of social network theory to examine similarities, social relations, and interactions between actors within a given network (Borgatti et al., 2018). Networks are described as “a way of thinking about social systems that focuses our attention on the connections or relations among the entities that make up the system” (Borgatti et al., 2018, p. 341). Social networks are structural and demonstrate the makeup of interactions among actors and are mapped out visually. The network “actors” can be comprised of individuals, companies, or any other entity defined by a researcher; this paper focuses on individuals with IDD therefore the term “individuals” is used. Individuals within a network are typically represented as a circle in a social network analysis diagram (called a sociogram). Relationships between the individuals can be indicated using an edge or a tie (which appears as a line) between the individuals. Relationships that are examined are defined by the researcher and can include similarities between the individuals (e.g., connections between individuals who are the same gender, or between those with disabilities and those without disabilities), relational roles between the individuals (e.g., connections between family members), or relational events between the individuals (e.g., who goes to whom for advice) (Borgatti et al., 2018).

Social networks are constructed via two primary means of data collection: social network surveys and ethnographic observations. Data can be collected through a “name generator” written survey or interview, where an individual is asked to name others within the given parameters and then describe the relationship of interest among the others. For example, a person can be asked to name everyone within their department at work whom they go to for advice.

Data can also be collected through ethnographic observation. For example, a researcher could observe a classroom and note which students interacted with each other, who initiated the interaction, and how frequently interactions occurred. Data from both methods of collection can be graphed visually on a sociogram so the network can be analyzed. Social network analysis can help clarify a variety of characteristics about the network as a whole or an individual's position within the network.

4.2.3 Centrality in Social Network Analysis

One foundational concept in social network analysis is the idea of centrality. Centrality, at its most basic definition, is a measure of an individual's position within a network (Halgin & Brass, 2021). The level of centrality is viewed in how an individual's presence within a given network influences the structure of the network overall. In general, the higher the degree of centrality of an individual, the more connected the person is to the rest of the individuals in the network, and thus the more influence that individual is thought to have over the whole network. In social science research, centrality has been used as a predictor of positive social outcomes for individuals (Borgatti et al., 2018). For example, high centrality can cause an individual to experience a "sense of being" (Freeman, 1987, p.220) in the network, while low centrality will cause the person to feel "cut off from active participation" in the network (Freeman, 1987, p. 220).

There are many different types of centrality but the most basic type is degree centrality. Degree centrality is the number of ties that an individual has to others within a network. For example, in a small network comprised of five individuals, an individual (A) who has more connections with other individuals (with a maximum of four ties) would have a higher centrality than those who were only connected to one or two others (see Figure 1). If the ties within the network represented "friendship" or "likeability," a higher centrality would indicate higher amounts of friendship or likeability within the network. However, ties can also indicate negative relationships, such as "dislike" or "distrust". Therefore, centrality and the meaning of one's centrality within a network needs to be interpreted in respect to the ties that are being examined. According to social network theory, a higher degree centrality on positive relationships can indicate social capital, or power (the ability to influence others) (Borgatti, 2019).

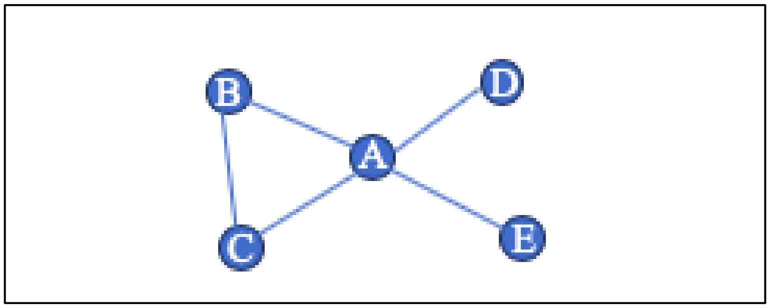


Figure 4.1: Degree centrality example. Circles indicate individuals; lines indicate relationships. Letter "A" has the highest degree centrality since "A" is connected with the most individuals in the network compared to any other individual in the network

4.2.4 Applying Social Network Theory to Social Inclusion of Individuals with IDD

Research using social network analysis has demonstrated that the social network makeup of individuals with IDD differ compared to the social networks of their peers without disabilities (Chamberlain et al., 2007; Van Asselt-Goverts et al., 2015). Van Asselt-Goverts et al. discovered that individuals with IDD have fewer people overall in their networks, have known people in their network for a shorter amount of time compared to peers’ social networks, and have more professionals in their networks such as therapists and counselors as compared to same-aged peers without disabilities. Furthermore, they discovered that individuals with IDD were less satisfied with their network compared to their peers (2015).

Chamberlain et al. (2007) conducted a similar study examining the characteristics of the social networks of children with autism spectrum disorder in a classroom setting and compared the networks to those of their same-age peers. The researchers used social network analysis with surveys to measure the amount of peers identifying an individual as a friend and calculated each individual’s centrality from the networks that were constructed. Chamberlain et al. also correlated student’s network data with a loneliness scale and a friendship quality scale. They found that children with autism spectrum disorder had less reciprocated friendships and were more on the periphery (less central) of their network compared to their peers without an autism spectrum disorder (Chamberlain et al., 2007).

While research has demonstrated there are differences in the social network makeups of individuals with IDD compared to their peers, an association between the degree of social inclusion using centrality to measure the social interaction component of social inclusion has not been presented before. Krieder et al. (2015) made an indirect connection using social network theory in their study which examined the social networks of individuals with developmental disabilities (DD) with a measure of activity participation, but they did not link this to the construct of social inclusion. Krieder et al. (2015) examined the networks of individuals with DD including the composition of the network, density of the network, and the strength of ties within the network and compared that with the Children's Assessment of Participation and Enjoyment (CAPE). They discovered that individuals who had more non-relative peers and acquaintances in their networks engaged in more activities overall (Krieder et al., 2015).

Chamberlain et al. (2007) and Krieder et al. (2015) both examined centrality of individuals with IDD, but they did not directly link the concept that degree of centrality can help indicate an individual's degree of social inclusivity and thus social inclusion. Using Simplican et al.'s (2015) model of social inclusion, centrality within a group setting may be an effective way to understand and measure the degree of social interaction component of social inclusion for an individual with IDD in a group setting.

In order to examine centrality among people with IDD, name generating surveys (such as used in Chamberlain et al. and Krieder et al.) or carefully documented ethnographic observations of the interactions between individuals within the network could be used. However, using a self-report measure such as a name-generator survey to construct a social network may present with challenges when used with the IDD population (Fujiura and the RRTC Expert Panel on Health Measurement, 2012). Individuals with IDD may struggle with generating names from memory or understanding what the survey tools may be asking (Fujiura and the RRTC Expert Panel on Health Measurement, 2012). Using ethnographic observation (when possible and appropriate to the research questions) to document the social networks for individuals with IDD may be a more accurate measurement of social interactions between individuals compared to self-report data through name generating surveys (Freeman & Romney, 1987). For example, in an ethnographic observation of a school classroom comprised of children with and without disabilities, if a child was more socially interactive in the group, he or she would be observed as having more exchanges with others in the group. This interaction would cause that child to have a higher degree of centrality compared to others in the group who were socially included to a lesser degree.

Given that social network theory indicates that individuals with a higher centrality can cause an individual to experience a “sense of being” (p. 220) in the network (Freeman et al., 1987), it could be argued that having a “sense of being” within a group and having high interactions with others in the group are positive indicators of social inclusion. Ultimately, analyzing social network data using either means of data collection can help understand an individual’s centrality within a network, which will help provide a measurement of social interaction for individuals with IDD. Measures of participation can then be triangulated with the outcomes of the social network analysis to determine how socially included a person is compared to their peers.

4.3 Implications for Research and Practice

Social network analysis is an important starting point for helping to better understand the construct of social inclusion of people with IDD. Using social network analysis to examine social interaction, combined with a measure of participation (such as the COPM, GAS or others) to assess social inclusion, allows researchers to compare results across studies to help establish best practices with high rigor (such as the use of systematic reviews) for increasing social inclusion for individuals with IDD in a variety of contexts. Additionally, a better understanding of the construct of social inclusion is important for advancing policies and legislation to benefit the largest group of stakeholders for social inclusion- individuals with IDD- as well as their families and caregivers. Ensuring that an individual with IDD is not socially excluded from society has important health and social implications; being able to measure and understand degree of social inclusion can help to promote positive outcomes in well-being and quality of life.

With training, disciplines including educators, therapists, and rehabilitation professionals, may use this analytic technique to guide and evaluate the effectiveness of interventions. For example, if an educator used social network analysis and a measure of participation such as the CAPE-PAC, they could determine that a child with IDD in their classroom was not being socially included. This could result in interventions by the educator or a referral to a therapist to increase the child's level of social inclusion.

However, there are few available interventions in the literature to increase social inclusion, likely in part because of the lack of ways to measure social inclusion. Adding a peer "buddy" (Carter et al., 2009) for a child with a disability to increase their social interaction is one option that is suggested in the literature. Another option is to leverage existing relationships in the network. For example, in social network theory there is a concept of "opinion leaders" – individuals that, because of their centrality within a network, have a high influence over the behaviors of others in the network (Cho et al., 2012; Kim et al., 2015). If opinion leaders were educated about the benefits of social inclusivity and were encouraged to be more socially inclusive of individuals with IDD in the network, it is theorized that inclusivity would improve for network as a whole including for individuals with IDD. This highlights a challenge of interventions for social inclusion, in that the interventions may need to be targeted to the specific setting, community, or other individuals in order to be effective.

4.4 Limitations

Although social network analysis has great promise in helping to measure social inclusion of individuals with IDD, there are several limitations to its use as an effective measurement tool. First, using ethnographic observation for data collection is time consuming and can only be applied in contexts with groups with specified boundaries (such as a classroom, club, or other community group). It would be impossible to observe an individual's entire social network (i.e., everyone that person knows). To analyze a whole network, a survey or other method would need to be utilized instead, which presents its own challenges with individuals with IDD who may have difficulty participating in a survey approach. Results would have to be interpreted carefully and in collaboration with the individual with IDD to understand the individuals' experience with being included in their whole network.

Using centrality as a measure of social inclusion can help identify social interaction in specific group settings, but the definitions of social inclusion and methods for using social network theory to understand interaction in larger settings and networks needs to be further refined and developed. Deciding to use degree centrality over other methods of centrality in social network analysis would have to be weighed according to the outcomes the researcher was trying to analyze. Additionally, conducting social network analysis research is an advanced skill that requires extensive training and education that may not be feasible for many researchers or clinicians to acquire.

Lastly, social network analysis only measures the social interaction component of social inclusion. Therefore, additional data needs to be collected to understand the participation component of social inclusion as described by Simplican et al. (2015). It is also recommended that this method of measuring social inclusion be tested to better understand the individual’s experience within the group to confirm validity of the results with the individual feeling included in the group. This could come in the form of qualitative methods such as interviews. However, as with utilizing a survey method for data collection, this may be difficult for individuals with IDD depending on their level of communication.

4.5 Conclusion

Research has demonstrated that individuals with IDD continue to experience barriers to social inclusion (Abbott & McConkey, 2006; Asselt et al., 2015). Social exclusion can lead to poor health, employment and quality of life outcomes for individuals with disabilities (Amado et al., 2013; Evens & Repper, 2001; van Bergen et al., 2018). Increased social inclusion leads to increases in overall quality of life (National Council of Social Service, 2017). However, measuring social inclusion for individuals with IDD has proven to be difficult. There lacks a unified definition for social inclusion for individuals with IDD in the literature. This makes measuring social inclusion and using social inclusion as an outcome measure difficult to determine the effectiveness of inclusion interventions.

This paper proposed using social network analysis in conjunction with a measure of participation to measure social inclusion. While there are some limitations, this methodology provides a starting place for research on social inclusion for individuals with IDD. Providing a measure of social inclusion will allow researchers to determine the effectiveness of interventions targeted at increasing social inclusion for those with IDD, ultimately leading to increased social inclusion for those individuals. Future research should focus on confirming the use of this method by comparing perceived self-inclusion with the approaches outlined in this paper**.**

CHAPTER 5. UNDERSTANDING THE EXPERIENCES OF FAITH-BASED VOLUNTEERS SERVING CHILDREN WITH DISABILITIES IN THEIR FAITH SETTINGS

Faith-based settings, such as churches, temples and synagogues are areas of routine community participation for many individuals in the United States (Kessler Foundation 2010). Being a member of a faith community is often an integral part of life for families and individuals of all abilities (Ault et al., 2013a). In general, the benefits of inclusion within a faith community include greater longevity of life, improved stress management, a greater sense of meaning and purpose in one's life, and feelings of connectedness (Ault et al., 2013a; Carter & Boehm, 2019; Poston & Turnbull, 2004; Vogel et al., 2006).

While faith participation can be meaningful for everyone, individuals with disabilities face environmental and social barriers that limit them from participating in their faith communities (Slocum, 2016). Research has demonstrated that people with disabilities participate in faith settings less often compared to their non-disabled peers (Ault et al., 2013a). In 2009, the American Association on Intellectual and Developmental Disabilities (AAIDD) issued a statement that individuals with disabilities should be presented with equal opportunities to engage in activities that promote their quality of life. Similarly, the Americans with Disabilities Act (ADA) prohibits discrimination of people with disabilities and aims to ensure that people with disabilities have equal opportunities to "participate in the mainstream of American life" (ADA.gov, n.d. par 1), of which faith participation would be included. Literature on supporting individuals with disabilities in the community exists within the context of school participation, work and living, but little is known about how to support the faith participation of those with disabilities (Slocum, 2016). The presence of a disability should not be a barrier to having opportunities to engage in activities that promote quality of life and build social relationships such as participating in a faith community (Ault et al., 2013a). However, because barriers persist for people with disabilities in faith-based settings, there is a need to increase supports for individuals with disabilities and their families to participate in their faith setting.

One-in-six children between the ages of 3-17 are affected by disability in the United States, and this number continues to increase (Centers for Disease Control and Prevention [CDC], 2020). The presence of childhood disabilities effects a variety of individuals and transcends socioeconomic, racial, and ethnic status (CDC, 2020). Children with disabilities experience a range of medical, behavioral, developmental, learning, mental health, or other challenges in their daily lives (Mauro, 2020). Due to the variety of challenges that children with disabilities may exhibit, it can be difficult for individuals to care for them without training or having prior experience (Whitmore & Snethen, 2018). In faith-based settings, volunteers who often lead the children's programming do not have formal training to manage or assist children with disabilities (Vogel et al., 2006). Therefore, it is imperative that researchers seek to understand faith volunteers' experiences in serving children with disabilities to examine the current supports in place, ongoing barriers, and desired resources needed to facilitate participation for individuals with disabilities and their families.

5.1 Impact of Faith Participation on Individuals with Disabilities

Research on spirituality and individuals with disabilities indicates that a life that incorporates spirituality in the context of a faith-community can provide one with increased inner strength and meaning, increase one's quality of life, and provide support

(Carter et al., 2016; Liu et al., 2014; Sullivan & Aramini, 2019; Zhang & Rusch, 2005). Parents and caregivers reported that being in a faith community offered benefits for their children with disabilities such as support, social experiences, and learning experiences (Ault et al., 2013a). Similarly, O'Hanlon discussed that participation in a faith community can help families cope with the struggles they face because of their child's disability and it can help ascribe meaning to their child's disability (2013). Many parents of children with disabilities that are involved in faith communities want their children to have the opportunity to be involved in activities and faith-based education, however one-third reported they felt unwelcomed or unsupported in these settings due to their child's disability (Ault et al, 2013a; Sullivan & Aramini, 2019).

5.1.1 Barriers to Faith Participation

Families of children with disabilities have reported numerous barriers to participation in faith-based activities including minimal congregation acceptance, lack of appropriate opportunities, absence of peer inclusion, limited supports, and decreased church leader knowledge and education (Ault et al., 2013a; Miller & Skubik-Peplaski, 2020). Unfortunately, some members of the faith community believe the environment in a faith setting is too fast paced for a person with a disability to be able to successfully participate, and therefore they oppose the integration of individuals with disabilities in congregations (Patka & McDonald, 2015). Some barriers that have been noted include challenging behaviors exhibited by individuals with disabilities, negative attitudes from those in the faith community, and a lack of adequate training to support the children with disabilities (Ault et al., 2013a). Additionally, studies indicate that children with disabilities are not always given the opportunity to be in a group with age-appropriate peers in faith-based activities (Sullivan & Aramini, 2019). Children with disabilities are instead often placed in disability-specific classrooms or classrooms with younger children that more closely matches the developmental level of the child with a disability instead of with their peers (Ault et al., 2013a).

Youth with disabilities were found to have limited involvement in peer youth groups, which is a missed opportunity for relationships and learning (Carter & Boehm, 2019). Although helpful supports were identified by parents, Carter et al. (2016) found almost half of the parents reported that no supports were available in their own faith community. Other studies have demonstrated that about one-third of parents of children with disabilities have indicated they have changed faith communities due to a lack of inclusion supports for their child, and about one-half indicated they stopped participating in the community altogether (Ault et al., 2013a).

5.1.2 Family Burden

Often the role of encouraging disability inclusion in a faith setting is initiated by the families of the children with disabilities themselves. Parents may never get asked by faith leaders about the best ways to support and include their child in these faith-based activities (Ault et al., 2013a). Many times a parent is asked to remain with their child with a disability in faith settings, thus limiting the parents' own faith participation, and also making it more likely that the family will stop their faith participation (Ault et al., 2013a; Poston & Turnbull, 2004).

To try to achieve a positive experience within a community, some parents have educated their faith leaders and the faith community while others have left faith communities to find one that would better include and support their child with a disability

(Ault et al., 2013a; Sullivan & Aramini, 2019). It is noted in the literature that most seminaries do not provide formal training on disability ministry (Carter & Boehm, 2019). Many parents have noted negative experiences including feeling that their faith setting was inflexible, unaccommodating, had unknowledgeable religious leaders and educators, and their child with a disability was ostracized or placed in an age-inappropriate placement (Ault et al., 2013a; Sullivan & Aramini, 2019). Many parents hope that inclusion in their faith community will give their child with a disability more social interaction and give the child an opportunity to be a part of the community (Sullivan & Aramini, 2019).

Supporting the needs and faith participation of those with disabilities in faith settings remains a challenge. It is imperative that faith communities provide guidance in supporting participation of youth within their worship services, and in learning or social activities with peers (Carter & Boehm, 2019). While many position papers and statements call for the inclusion of children with disabilities in faith settings, very few studies have demonstrated how to increase inclusion in this area. The volunteers in the faith settings are the ones that provide the supports and services to children with disabilities in the children's programing, yet little is known about their experience in working with children with disabilities in their setting.

5.1.3 Study Purpose

Children's programming in faith settings is often provided by volunteers from the faith community. Currently, it is unknown what the experience is of those volunteers who work with children with disabilities in faith settings. The purpose of this study was to understand the experiences of volunteers who worked with children with disabilities in their faith settings. The current study seeks to enhance the literature to find ways to support the inclusion and participation of children with disabilities in faith-based settings.

5.2 Methods

This study used a qualitative phenomenological design with a one-on-one semi-structured interview format. The use of a phenomenological design was appropriate to address the research purpose to gather information on the lived experiences of the volunteers serving children with disabilities in their faith settings. University Institutional Review Board (IRB) approval was initially received in the Fall of 2019. All data was collected during the Fall and Winter of 2019. Data analysis took place in the Spring and Summer of 2020.

5.2.1 Inclusion and Exclusion Criteria

Volunteers who “regularly” serve children with disabilities in their faith setting were the desired target for this study. Thus all volunteers interviewed must have served in a children's program within their faith setting for at least six months and at least four times within the previous six-month period. Additionally, volunteers must have been at least 18 years of age and had at least one identified child with a disability in their faith setting. Volunteers were excluded if they did not fluently speak English as translation services were not available for this study. No exclusions were made based on faith tradition. Written informed consent was obtained from all study participants prior to conducting the interviews.

5.2.2 Participant Recruitment

Purposive sampling with maximum variation was used to try to capture a wide diversity of responses. A flyer was sent to children's ministers and lead pastors of all faith traditions to distribute to their children's services volunteers to recruit interested participants within 200 miles from the researcher's location (Cincinnati, Ohio). All interested participants were asked to contact the researcher via phone or email to set up a screening appointment for inclusion in the study. Screening was performed via telephone by the primary investigator (PI). If participants qualified for the study and were interested, a time was set up to conduct the interview in person.

5.2.3 Data Collection

Data was collected using semi-structured interviews conducted by the PI. Interviews were conducted at a location chosen by the participant. The semi-structured nature of the interview allowed the researcher to utilize follow-up questions to clarify and gather more information as appropriate. The semi-structured interview questions were:

1. Tell me about your children's ministry program and your involvement with it.
2. What is your experience with having children with IDD in your children's ministry program in your faith setting?
3. Tell me about your experiences with children with IDD outside of your faith setting.
4. What type of participation do you think children with IDD might have in children's ministry program?
5. Tell me about some advantages that you see to including children with IDD in your ministry program.
6. Tell me about when it was difficult to incorporate a child(ren) with IDD in your ministry program.
7. Tell me about steps you or your children's program have taken to incorporate children with IDD in your faith setting.
8. What are some things that would be helpful for you as a children's volunteer to support children with IDD in your children's ministry program?

All interviews were audio-recorded, and the PI took field notes during the interview to clarify information during the analysis process.

5.2.4 Data Analysis

Data analysis took place in the Summer of 2020 over Microsoft Teams due to COVID-19 restrictions. Four student researchers in a Master of Occupational Therapy (MOT) program assisted with the data analysis process. The research team for data analysis was comprised of the PI and the four MOT students. The data collection and study design was completed by the PI. Data collection and analysis process followed Moustakas' (1994) process for phenomenological research. The four-step process included audio recording the interviews, transcribing the interviews verbatim, coding the interviews, and then examining the codes for broad themes that emerged (Moustakas, 1994). After the interviews were transcribed, members of the research team read through the transcriptions in their entirety and then analyzed the transcriptions to find significant statements relative to the study. These significant statements were quotes by the volunteers that the investigators felt were significant to the purpose of the study. These quotes were all compiled in a master codebook which was a large excel file and color coded to match statements that were similar. Overall, 29 separate codes were developed- see Table 5.1 below for an example of several significant statements with their codes. The codes were then analyzed by their frequency and similarity for the emergence of recurring broad themes and sub-themes. See table 5.2 below for an example of themes with codes. During the final step of the data analysis process, key findings were identified and recorded.

Table 5.1: Examples of significant statements arranged into codes

Examples of Codes	Examples of Significant Statements	
Want Parents/ Families to Have a Normal Supportive Experience	“And the particular family that has the daughter who is severely autistic, I think sometimes they feel very excluded as a family.”	“It’s important for the families.”
Impact of Environment on Participation	“I’m like, ugh, like the flooring is weird. Like, it’s got pretty deep crevices … what would we do if we had a bunch of wheelchair, um, or like I'm thinking kids with walkers like they’d get stuck all the time so it’s like things like that I just don't think that we're equipped or prepared for really or set up for success with.”	“We just borrow the classrooms. And the classrooms are so overstimulating.”
Fear of Working with Kids with Disabilities	“I don't know what I'm doing. I don't know how to, I don't how to connect with this child. I don't know how to interact with this child.”	“I think too the unknown for some people scares them.”
Difficulty with Complex Medical Needs	“The mom would basically have to pop out of service once, sometimes twice each time for [medication administration] to happen and then he would have to not be around other kids, so it wasn’t that we couldn’t accommodate, it’s that it was, we were starting to get into ‘well the mom might as well just watch online like she does already from home.’”	“I think too when it comes to some medical things, we’re definitely not prepared to be [PAUSE] help for anyone who would have any big medical needs.”

Table 5.2: Examples of Codes being combined to create themes

Examples of Themes	Examples of Codes	
Volunteers feel called to support children with disabilities in their faith settings	Volunteers want children and families to have a “normalized” experience	Volunteers think it’s important for kids without disabilities to be around kids with disabilities
Volunteers want more support to serve children with disabilities	Volunteers think training is needed	Environmental and activity changes are needed

5.2.5 Study Rigor

Fidelity of each interview transcription was independently assessed by two members of the research team to ensure accuracy. Transcriptions were examined to check for errors and ensure the text correlated exactly with the audio. A minimum total of twelve minutes of audio, four minutes at three different time periods, were examined and recorded per fidelity check. No content modifications were required following the fidelity checks.

The PI and two student researchers independently reviewed each interview transcript. The three group members who reviewed each interview met to discuss and come to a consensus on significant statements used for each interview. Triangulation was used with the PI's field notes to further develop an understanding and to increase the validity of the results. All members of the team participated in the coding and thematic analysis process until consensus was reached regarding the major themes and sub-themes. An audit trail was kept during the coding and theming process to verify the appropriateness of the themes throughout the process.

5.3 Results

A total of eight children's faith-based volunteers were interviewed for the study. Participants included two males and six females with the age range being 35-45. Participants had a range of 4-12 years of experience volunteering in the children's programming in their place of faith. Once saturation was reached no further volunteers were recruited. Characteristics of the participants are summarized in Table 5.3 below (pseudonyms used for all Participants).

Table 5.3: Participant Characteristics

Participant Pseudonym	**Volunteer Frequency**	**Types of Disabilities Present in Volunteers' Children's Ministry**	**Faith Tradition**
Petunia	1x/week	ADHD, Developmental Delay	Catholic
Jesse	2-3x/month	Autism, Down syndrome, Physical disabilities	Non-Denom. Christian
Hope	2x/week	Autism, Sensory Processing	Methodist
Brittany	2x/month	Down Syndrome	Non-Denom. Christian
Casey	1x/week	Cerebral Palsy, ADHD, Autism, ADD	Non-Denom. Christian
Maria	2-3x/month	ADHD, Deafness	Baptist
Jennifer	1x/week	Autism, ADHD, Cerebral Palsy	Church of Christ
Daniel	3-4x/month	Cerebral Palsy, ADHD, Autism, Global Developmental Delay	Non-Denom. Christian

Note: ADHD is Attention Deficit Hyperactivity Disorder; ADD is Attention Deficit Disorder

The thematic analysis revealed the emergence of three major themes and several subthemes from the data. The themes and subthemes can be found in Table 5.4 below. Each theme is explored in more depth in the text below.

Table 5.4: Themes and Sub-Themes

Major Themes	**Sub-Themes**
A Call to Support Children with Disabilities in Faith Settings	• Volunteers want the children with disabilities and their families to have a "normalized" experience • Volunteers think it is important for children without disabilities to be around children with disabilities • Not all volunteers are comfortable with serving children with disabilities
Faith Volunteers Want More Support to Serve Children with Disabilities	• Training is desired • Changes to the activities and in the environment are needed to support children with disabilities • Additional personnel are needed to support children with disabilities
There are Differences in the Type of Participation Individuals with Disabilities May Have in Faith Settings	• Inclusive Rooms • Separated Spaces

5.3.1 A Call to Support Children with Disabilities in Faith Settings

The participants reflected on why kids with disabilities may need to be supported in their faith settings. Participants overwhelmingly noted they want kids with disabilities and their families to have a normalized experience. One participant noted they believed in "making sure that they [children with disabilities] have a safe space to be themselves.” Another noted “I definitely think the biggest advantage is [the kids with disabilities] feel loved.” One participant shared how important it can be for children with disabilities to experience support from individuals and communities outside of the home. “Just because children with disabilities may need accommodations or extra support, it is still important that they feel like any other child in the faith community.”

5.3.1.1 Volunteers Want the Children with Disabilities and Their Families to Have a “Normalized” Experience

Three participants identified their desire to give families with children with disabilities a “normal” experience, such as the feeling of inclusion within their congregation and experiencing an uninterrupted adult service. One volunteer stated “Parents cry. Because there is nothing out there for parents to have the ability to do, like one lady, she said, ‘before the buddies program, my church was in the car.’” Another volunteer noted that “I think the families need some type of normalcy or feeling of acceptance. Because you feel so divided, such as a separate island. And so having them be part of what everybody else is doing can be very comforting.”

Several participants noted wanting to ask these families, “how can we help your family?” but felt unsure how to encourage those conversations. Participants felt it would be most helpful to have a partnership between parents, ministry leaders, and children’s program volunteers and teachers. Often families are in their own service during children’s programming, and one participant expressed that this allows the families to fully engage in worship and feel at ease with their child’s care. A few participants shared the value of giving parents the peace of mind that their child is well cared for and accepted so they can enjoy their own services. One participant reported:

> I want him [the participant’s child] to do what everybody else is doing. Not because I want him to be normal but because I want him to have the experiences...and I think the families to need some type of normalcy or feeling of acceptance.

5.3.1.2 Volunteers Think It is Important for Children Without Disabilities to be Around Children with Disabilities

Every participant in this study also noted there is an advantage of including kids with disabilities for the kids without disabilities. Participants identified specific advantages including exposure to children with developmental disabilities, normalizing the exposure to individuals with disabilities, and the similarities with their love for God. One volunteer stated that having children with disabilities in their room helped with “normalizing the experience of having kids who learn differently or who think differently, who see the world differently”. Another volunteer noted:

> You’re also teaching the other kids that, you know, God’s love doesn’t care if you’re, you know, in a wheelchair or running round the room, or standing in the corner flapping, or having a meltdown because you’re overwhelmed. Or if you can’t talk, or if you’re deaf… It also helps kids to see that God sees us all the

> same. And I think it's an important lesson for kids. And when you teach kids then you also teach adults.

Yet another participant stated:

> I think the biggest advantage is exposing the other children to children of varying abilities. And teaching them you know, to have a Christian heart, to have God’s heart and to treat and love others equally. I think that’s the biggest thing is recognizing that not everybody in this world has the same gifts. But that we can all use the gifts that we do have to serve God.

Another volunteer said:

> I think the advantage there is that you know they see that you know that we are all human race. So, just because you know somebody might walk a little different or you know, not be able to speak to you the same way somebody else doesn’t mean that they don’t have you know value and they don’t have opinions or emotions or feelings.

One last volunteer stated:

> I think that there’s an advantage for the kids that are not dealing with any kind of disability. I think there is a level of compassion and patience and just being immersed and seeing things that they wouldn’t normally see that could that’ll affect them and affect their heart, affect their brain, affect how they treat other people. It’s just, special needs, it’s a different kind of, um, [pause] they bring something different to the table.

5.3.1.3 Not All Volunteers are Comfortable with Serving Children with Disabilities

Many of the volunteers received a personal sense of reward or fulfillment for working with kids with disabilities but they recognized that not everyone felt comfortable working with children with disabilities because of how challenging it could be. One volunteer reflected that serving individuals with disabilities may get overlooked by many churches when he stated:

> I think there are a lot of things that churches can focus on and I think that [serving individuals with disabilities] probably gets overlooked a lot. Um, and I get it. If your leaders or the people, your people who are in control or leading your church, if they are not personally affected by it, it's probably not on their list of priorities.

Two volunteers expressed a fear of doing the wrong thing when working with children with disabilities:

> I think that's probably something that other people don't want to take that risk (of working with kids with disabilities) because they don't know. But all you can do when you fail is try again. You know, it's not, you're not hurting the child by trying to help them.

> Maybe people who don't have a lot of experience with special needs kids, its there's like a fear there. Um, like 'I don't know what I'm doing. I don't know how to I don't know how to connect with this child. I don't know how to interact with this child. I don't know how to meet his needs. I don't know how to minister to him.' Like there's this fear of the unknown. Or fear of um, I hate to say like not

> educated but like knowledge, having a lack of knowledge or something. Like if I don’t do this right I’m going to break something.

One other volunteer worried that other volunteers in her congregation may not feel they have the time to devote to serving children with disabilities:

> I think a lot of youth sponsors are already over extended. They’re all doing it as a volunteer position and I can see people saying ‘well I don’t have time to learn that’ or ‘I don’t have time to spend, you know five extra minutes doing that this way and that, you know I have my lesson and I have it set and we have this amount of time.’ So I think the challenge there is just like helping people see the value and taking the time and having that patience.

5.3.2 Faith Volunteers Want More Support to Serve Children with Disabilities

Every volunteer in this study wished they had more support in serving children with disabilities in their congregation. Desired support ranged from training needs, to more volunteer support, to changes in the environment, activities and curriculum. These identified supports are believed to enhance inclusion, as the volunteers felt they would be more adequately prepared to assist children with a variety of unique needs throughout the program including providing more individualized support.

5.3.2.1 Training is Desired

All eight of the participants recognized that training would be an effective tool to support themselves or others in working with children with disabilities. Participants specified ideas such as a “what if” training, reference guides, and specialized training about specific diagnoses. One participant stated "I think having, um, like a go-to resource that was like okay if, if you have a student with ADHD like some best practices that you can do right now… Like a really quick kind of reference guide." One participant discussed what she called a "What if" training. She described it as "let's just have a [discussion], essentially like a get-together. So like maybe [they volunteers] share their ideas or their experiences with each other right to help then maybe [the volunteers] feel more prepared or everybody feel more comfortable."

Every participant stated it would be beneficial to receive training or education in common diagnoses of children with disabilities, challenges they may have, and strategies to help them. One participant shared that even though they had a child with special needs of their own, their knowledge was "still very limited in terms of special needs of other types of children." Another noted:

> I'm sure some level of training. Like, when you sign up to be a volunteer, um, some level of "these are the type of kids, people you could encounter. These are some things to do to serve them. This is what you could do if you get in a position where you need more help."

Two participants also recognized a need for consistency with training, as there were often different volunteers or teachers providing the children's programming each week.

Another type of training that was identified as potentially being useful by three participants was training in managing difficult behaviors. One participant stated, "I'm not formally trained in behavior management, in those [situations in which a child was upset] types of situations it was, it was a difficult call for me to make on how to keep the child safe." One participant identified a training class offered outside of their faith setting which focused on situations in which behaviors were inappropriate or unsafe; however barriers such as pricing and location of the training were deterrents to taking the class. Another participant similarly noted they found a training course on behavior management, but it was going to cost around $900 which they indicated was prohibitive.

Lastly, “anticipating problems” describes strategies to support inclusion by providing information to volunteers, having a plan in place for challenging situations, and providing strategies/resources to assist with any anticipated problems. One participant stated, “I've learned with them that sometimes you really just have to let them get that energy out. Give them you know five minutes at the beginning of class or five minutes at the beginning Bible study…it seems to me like you know if you kind of give them that moment to themselves that they, they kind of come back in.” By anticipating problems before they arose and by teaching others to do so, volunteers could best assist children by identifying the best possible solutions before a challenging event occurred.

5.3.2.2 Environmental and Activity Changes are Needed to Support Children with Disabilities

Participants proposed a range of suggestions for supports they felt could improve accessibility and participation of children with disabilities in their children’s programming. Suggestions varied from changing the environment, implementing activity modifications, creating a buddy system, being flexible with expectations/participation, adapting the curriculum, providing additional volunteer supports, having space/environment to facilitate inclusion, and anticipating problems.

With regards to the environment, several participants stated their environment acted as a barrier for children with disabilities. According to one particpant:

> Because of the overstimulating environment it adds an extra challenge. The parents want him fully included but it’s also setting him up for failure at times. Because before we even go back to class everybody, everybody in the program meets in the cafeteria- and says a prayer together and at the end they all scream “God is good, all the time, all the time, God is good!” Which for a child [with disabilities] is so overstimulating.

Another stated:

> We do have a child in a wheelchair, and sometimes there may be some physical areas that we have to kind of have to pick the child up and then kind of cart the wheelchair around something in order to get them towards where they need to be. You know? Little things like that.

One volunteer noted that while their environment was not a barrier, they would like to have things available in their environment to help facilitate participation. She stated:

> I think it would always be nice to have like equipment whether it’s, um, I’m just thinking like the beanbag chairs and the sort of things we’ve had that helped. You know knowing what helps each student having that space they can use those in. I’m not saying that you know all churches have to have super massive amounts of equipment, but you know just having some basic things that can help.

Some faith-based children’s programs have begun to integrate their own supports such as the “buddy system” which is a program that pairs a non-disabled “buddy” to a child with a disability. Buddy programs aim to provide additional assistance and guidance as the individuals with disabilities participate in the program. One participant stated that, “anytime we have a service, we have buddies” with the hopes that this specific system supports positive experiences with inclusion and participation.

Participants identified “flexibility with expectations/participation” as an active step towards inclusion of children with disabilities. Two participants suggested that some children may need the environment to be a certain way for them to learn best. One participant added that some children may benefit from flexibility with how they are presented with material, and it should be normalized this is still okay as the children are learning in their own way. One example of flexibility was reported as describing to parents what the atmosphere is going to be like for their child, so if they felt it might be too much for their child then modifications could be made to ensure they were comfortable. One participant noted:

> If they're [the child with a disability] off in the corner playing with play-doh instead of sitting on the carpet you know, singing the song- they're still hearing the song, they're still part of the group, they're still feeling loved. It doesn't have to be exactly what the lesson plan says it was. I think some flexibility training for volunteers, just because the lesson says you have to teach them about the Ten Commandments, doesn't mean you have to sit down and teach them about the Ten Commandments.

An adapted curriculum was another notable suggestion made by several participants. An adapted curriculum could offer more individualized instruction with joint teaching strategies to modify the task to increase inclusion of all children within the same program. One participant shared they often used an “adaptive program book” that they purchased through their faith setting’s larger organization, which could be used to modify the learning material and aid with finding the best learning approach for individuals with disabilities. Another participant stated they did not use a “special curriculum”, but they modified the original curriculum, so the content was consistent with what the non-disabled children were learning.

5.3.2.3 Additional Personnel are Needed to Support Children with Disabilities

One of the most common suggestions included the need for additional volunteer supports. Church personnel/volunteer limitations were discussed by participants sharing they did not always have the “right” people, and faith volunteers had various levels of experience and dependability which made it a challenge. One participant emphasized this by stating, “but [volunteers] definitely just maybe get through the Sunday versus it being, you know a really good learning environment kind of Sunday.” One volunteer stated that their children’s program struggled to get consistent workers in general:

> In our youth programming we have a hard time getting consistent [workers]. So most of the time when I’m with the group it’s me and a bunch of children. Whether it’s you know five kids, ten kids, sometimes 25 kids, I’ve been known to be left alone. And I feel comfortable with that but there are days where I’m thinking it’d be really nice if there were you know somebody in here when ‘this’ happens or ‘when this person gets overwhelmed so I can step out with them’.

Similarly another noted that:

> [Kids with disabilities] probably could still be able to do a lot of our activities it would just take a little bit more help in the sense of staffing, or, because you really, I feel like it would almost need to be one-on-one.

Lastly, another stated that: “You know there, there’s a lot of needs there and in terms of individualized attention and care for a child with special needs. Um, it requires more volunteers. It requires more energy. It requires more intentionality from those volunteers.”

5.3.3 There are Differences in the Type of Participation Individuals with Disabilities May Have in Faith Settings

The last theme that emerged was that there were differences in the types of participation individuals with disabilities may want and/or need in faith settings. Throughout the interviews, participants talked about this tension between having inclusive rooms and separated spaces for children with disabilities.

All eight participants indicated that children with disabilities should be included to some degree but had differing views on what that practically looked like. One participant spoke of a child’s experience of inclusion in her setting as the child was well-liked by her peers and had her peers as “brotherly and sisterly protectors.” There were other experiences though where kids with disabilities did not experience this, where “the kids in general had a harder time accepting” them. Several participants agreed that children with disabilities were “capable of doing most if not all the things that other kids, the ‘typical’ kids can do.” The participants recognized the children should be included in ways that were comfortable for them, and then from there modifications or accommodations could be made. One stated:

> I want them to be as included as comfortable and as possible. For what we can support them with. That is kind of my thinking. Now I know churches have like

> special programs for some of the more severe disabilities and things like that. And that's cool too. I feel like there's gotta [sic] be kind of a marriage between what does the family want, what does, what can the church support, and then how can that be best played out.

A participant also noted that, "when a student's already having a hard-enough time, you know with their own internal stuff, why separate them and make them feel isolated, unless isolation is something that they absolutely, you know, need for their comfort level." Another stated that "[kids with disabilities] need to be fully included. I think the goals need to be a little different than the typical, because it's such a short time frame, right? You know we only have them for one hour a week." One last participant stated that:

> I'd like to see them be afforded, you know, like any other child would… I'm a believer in kind of the integrated type of setting, right. Not secluding children with special needs away from other kids.

It is of note that no participants in this study indicated that children with disabilities should be completely excluded from children's programming within faith-based settings.

The participants discussed the level of participation that individuals with disabilities currently have in their faith setting, with some describing it as "limited participation" and others stating their program had full inclusion. One participant described the need to understand what aspects may keep children with disabilities from participating in church services and other related activities. A few participants recognized that some of the children with disabilities may attend inconsistently and only participate in the faith programming when they felt comfortable. It was mentioned by some participants that their faith settings typically offered a few opportunities each week for children, but parents may not have their children attend for reasons not always known.

Several participants identified a need for “separate programming or space” for children who were easily over-stimulated and would benefit from a separate safe, consistent, and controlled environment. One participant described having a separate space which contained sensory materials to help children to calm down. Another participant described their “buddies program,” a completely disability-specific separate program from the regular children’s programming. There were differing opinions about whether children with disabilities should have separate groups or if they should be included with those without disabilities. One participant shared they thought there were times and situations when it was not the best for the child to be in a regular class, while another participant noted they had “problems with the notion of these children having their own [separate] class.” Another participant made a point that “adults have prayer rooms so why can’t the kids have a space where they can go and meditate or just relax. I think there’s room to have special events maybe just for the students who have different needs.”

5.4 Discussion

The results of this study highlight the importance of understanding the volunteer experience of working with children with disabilities in their faith settings. By understanding these experiences, researchers and other stakeholders such as faith leaders can examine ways to support the volunteers to increase inclusion for children with disabilities in these settings. The participants shared their churches’ children’s programming, their experiences with children with disabilities within and outside of the program, their ideas about the type of participation that children with disabilities can have in the children’s ministry program, advantages and challenges to including children with disabilities, steps their children’s programming have taken to incorporate children with disabilities, and ideas about what would be helpful as volunteers to support children with disabilities.

5.4.1 (Some) Volunteers Feel a Call to Serve Children with Disabilities

The volunteers in this study were eager for children with disabilities to have an experience similar to the children without disabilities, but often felt inadequate or uncomfortable doing so. Furthermore, the volunteers recognized that not everyone who serves in children’s ministry feels a call to support children with disabilities in their settings. It is of note that of the participants who responded to the recruitment efforts for this study, all seemed to have a passion to support the participation of children with disabilities in their faith setting. It is hypothesized that those who work with children with disabilities in their faith settings but do not view it as a call or personal passion may not have responded to recruitment efforts. Although the volunteer experience has never been examined before, frequently parents have noted they do not feel like their child with a disability is welcomed at their faith setting (Ault et al., 2013a; Carter, 2020) making it unlikely that all children’s volunteers feel the same as participants in this study. Likewise, Patka and McDonald (2015) found that some religious leaders feel that individuals with disabilities cannot conform enough to the congregation’s way of doing things and therefore it would be too difficult to include them. The enthusiasm of participants in this study for including children with disabilities is an encouraging finding.

There seems to be a disconnect between families and faith leaders when it comes to feeling welcomed and included in the church. Families with children with disabilities want to feel welcomed but often don’t, yet there are many faith leaders (such as those who volunteered for this study) that would like to serve more children with disabilities in their faith setting. Part of the disconnect may come from faith volunteers feeling unequipped to serve children with disabilities and therefore are afraid to “advertise” that they can serve children with disabilities. This supports our finding that volunteers desire support to improve their ability to successfully include children with disabilities in the programming.

5.4.2 Volunteers Would Like more Support in Serving Children with Disabilities

The volunteers felt it would be helpful to have training or resources available to feel better equipped to serve children with disabilities in faith settings. Similar to Poston and Turnbull’s (2004) study findings, there was an emphasis on the importance of providing training opportunities that are relevant, frequent, and not outdated. However, as one volunteer noted, finding trainings has proven difficult to find or too expensive for their congregation. Other studies have similarly found that some type of formal training or provision of resources for faith volunteers would be helpful (Ault et al., 2013a; Ault et al., 2013b; Carter et al., 2016; Hobbs et al., 2016) but these resources remain elusive. There are larger religious organizations that exist and already provide content and curriculum for the regular programming for many churches (such as Lifeway, the Gospel Project, Think Orange, and Group). Many of these organizations also have annual conferences where trainings are provided on regular faith-based programming. These organizations could be an avenue for disseminating trainings or materials for disability inclusion to be made more readily available to faith organizations. There are some smaller disability specific organizations that support the inclusion of people with disabilities in faith settings, such as Joni and Friends and SOAR Special Needs. However, these organizations may struggle to connect unless the faith settings specifically seek out ways to make their programming more inclusive. Additionally, there is a need for frequent trainings. As this is a volunteer structure, it is not uncommon for there to be a high turnover for volunteers (as compared to paid employees, for example). Therefore, a one-time training may not be sufficient. Trainings that occur regularly and often (such as twice a year), or a train-the-trainer model where the children's pastor was trained and then could train the new volunteers as they joined the team, are important considerations. However, these options rely on finding appropriate, accessible, cost-effective trainings.

The volunteers felt they could better support the inclusion and participation of children with disabilities in their faith setting if they were able to use various strategies, including modifying tasks, implementing programs such as the buddy system, using adapted curriculum, having the availability of different spaces or environments, and anticipating problems. However, most volunteers do not have the training, skills or knowledge to be able to implement these techniques (Poston & Turnbull, 2004). Partnering with professionals in the congregation who have expertise in this area, or seeking out trainings or other resources to learn strategies such as these would be invaluable. For example, asking an occupational or physical therapist to evaluate the classroom space for physical accessibility and sensory properties which may have an impact on a child's participation. Teachers and special education teachers in the congregation may be able to provide some simple classroom management strategies or may have suggestions for adapting the curriculum that may help all of the children participate more. One participant in the present study explained she was an occupational therapist and in her congregation she found and used an adaptive children's program for children with disabilities. Additionally, her expertise as an occupational therapist allowed her to determine modifications and accommodations that a child with a disability may need in her setting.

5.4.3 Types of Inclusion

While it is not the prevailing position, there has been some discussion in the education world that perhaps the idea of “inclusion” for children with disabilities in special education has gone too far and some students with disabilities need to be in more specialized programming to be successful (Gilmour, 2018). It was interesting to note that just like the debate about full inclusion versus specialized programming in the education system, it appeared that the volunteers and faith-settings were as equally conflicted about what was the best approach to serve individuals with disabilities. Many of the volunteers wanted children with disabilities to be fully included to the extent that was comfortable for the child. They also recognized that sometimes it may be beneficial to have separate spaces or programming but only for the benefit of the child with a disability, not out of convenience for others. Because there is a wide range in disability type and level of impact, this is a debate that will likely continue in all aspects of society in determining the best approach to including individual people with disabilities without making blanket provisions or determinations. As the education system continues to evolve in how it supports children with disabilities, faith settings can look to their examples to see if there are feasible options that the faith settings can also implement to support children with disabilities in their programming.

5.4.4 Implications for Faith Settings

Volunteers who participated in this study consistently endorsed the importance of advocating for the inclusion of children with disabilities and educating other members of the faith community (such as leaders, families, other staff) on why children with disabilities should be able to participate just as any other child can. The advantages and importance of including these children in faith settings should be highlighted, and conversations are encouraged to take place between the families of children with disabilities and faith community members to discuss how to overcome barriers to inclusion. Ault et al. (2013a) discussed that having a person within the faith community who acts as a champion for inclusion of those with disabilities can help bridge the gap between the needs of the families who have children with disabilities and the supports of the church. Since volunteers feel unequipped to serve children with disabilities they may not be comfortable approaching families and initiating conversations. This is another avenue that a professional within the congregation such as a therapist may be able to help facilitate supports. Volunteers also felt it may be helpful to organize and implement a system of disability disclosure by the families. Volunteers noted that they wished the knew more information about a child with a disability, or whether a child had a disability but weren’t sure how to request that information from the families in a compassionate respectful way. Volunteers noted they wanted a way to encourage disability disclosure by the families embedded into their normal “intake” processes such as getting the child’s name, allergies, age, etc. Implementing a system of disability disclosure may also help to facilitate conversations about how to best support children with disabilities with the families.

Given the results of this study and previous research findings (such as Ault et al., 2013a; Carter et al., 2016), it is important for volunteers in faith settings to discuss and have conversations with faith community leaders when they feel they need more resources or support to be able to better include children with disabilities in their faith settings. Examples discussed in the interviews were knowing how to manage difficult behaviors, overcome environmental barriers, or better understand a child’s specific needs. The open communication between the volunteers and their faith leaders can help the volunteers to feel more supported and better understand strategies to ensure more participation, understand what kinds of supports they can offer, and determine how satisfied the families currently are with their child’s experiences when working with children with disabilities.

Volunteer turnover in faith settings can make trainings and conversations to support disability inclusion difficult. However, Wymer stated that part of good church volunteer retention is making sure volunteers feel supported and equipped to do their roles (1997). Often, individual volunteers in faith settings may lack the authority to systematic changes in their settings, and therefore would also need leadership support from those within their faith setting to implement strategies and changes such as those mentioned above. Poston and Turnbull (2004) stressed that volunteers should advocate for additional supports for themselves to develop a ministry that is attentive to the needs of these children with disabilities and their families. By holding space for conversations and being more aware of the needs of the volunteers, leaders within the church may be more sensitive to ways to support volunteers in the future, thus bridging a gap that exists in serving children with disabilities. Additionally, faith communities can strive to actively seek feedback about their services from families that have children with disabilities to help with continual improvement as well.

5.4.5 Limitations

One limitation in this study was the homogeneity of the sample. The participants were all Caucasian, middle aged (between 25-50) and confined within 200 miles of Cincinnati, Ohio, creating a limited geographical range which altogether may limit transferability. While saturation was reached with data collection, the limited geographical range and cultural influences could limit the transferability of these results to other cultures or geographical areas.

Most participants in this study had an interest in working with kids with disabilities even though they did not all have formal training in how to do so. This may have biased the data as those who did not have an interest in working with children with disabilities likely did not respond to the recruitment efforts. Additionally, all study participants had some experience with people with disabilities outside of their faith setting. It is unclear if those who felt more comfortable working with children with disabilities in their faith setting were more likely to respond to the recruitment efforts. It would be pertinent to know if individuals who did not have outside experience working with children with disabilities shared the same views on their experiences in serving children with disabilities in their faith setting. One way of exploring the experiences of other volunteers who did not respond to the recruitment efforts for this study could be through the use of anonymous surveys which people may feel more comfortable completing honestly compared to an interview.

Lastly, there is risk for potential cultural bias from the research team members, as they were all members of Christian faith communities. There is a lack of cross-cultural knowledge and understanding of the dynamics of other faith settings. Other faith traditions beyond Christianity were targeted during the recruitment process to try to gather more information from other traditions, however only those in Christian faith traditions responded. This may be due to the fact that the PI of the study is an “outsider” of these faith traditions and also had disproportionally more connections to Christian faith traditions. The study does not provide transferable findings to large populations but rather gains further insight into the need for continued research.

5.4.6 Future Research

The findings support the need for further research to better understand interventions targeted to supporting the volunteers that serve children with disabilities in faith settings. Additional research is needed to explore the application of possible interventions that successfully facilitate increased inclusion and participation for children with disabilities in faith settings. Further exploration could include volunteers of more diverse faith communities and interviewees who live in other parts of the country to help with transferability of results. Further research will provide an opportunity to integrate programs that could be beneficial to improve volunteer competency and facilitate full inclusion for children with disabilities within their faith setting.

5.4.7 Conclusion

The volunteers from this study revealed that, consistent with other literature, they presume children with disabilities and their families face challenges within their faith communities. The volunteers proposed they would like to improve their skills and techniques to better support children with disabilities within their programs. The ideas shared in this study could be beneficial to determine the most effective guidelines, training and education, coaching, and strategies to implement within faith settings to increase accessibility and participation of children with disabilities. Leadership in faith settings may want to consider providing effective guidelines, support and strategies to their children's volunteers so they are best able to meet children's needs regardless of their diagnosis or disability.

CHAPTER 6. THE EFFECTIVENESS OF AN OCCUPATIONAL PERFORMANCE COACHING INTERVENTION WITH VOLUNTEERS TO SUPPORT THE SOCIAL INCLUSION OF CHILDREN WITH DISABILITIES IN FAITH SETTINGS

As mentioned throughout this dissertation, studies have demonstrated that individuals with disabilities participate in faith-based services and activities less often compared to their non-disabled peers (Kesseler Foundation, 2010; Poston & Turnbull, 2004). However, studies have also indicated that faith participation is as important to those with disabilities as it is to the general population (Ault et al., 2013a; Poston & Turnbull, 2004). Thus, the lack of participation for individuals with disabilities in faith settings is not due to a lack of interest, rather it is due to a myriad of barriers they face (Poston & Turnbull, 2004). Children with disabilities similarly participate in faith-based settings less often compared to their non-disabled peers (Ault et al., 2013a). Over half of parents of children with disabilities indicated their congregations were not supportive of their child with a disability, and almost one third of families of children with disabilities have left a place of faith due to their child not being supported (Ault et al., 2013a).

Children's programming during weekly worship services in faith-based institutions often rely on volunteers to provide instruction and services, including to children with disabilities who may attend. Previous studies demonstrated that volunteers and children's pastors that run the programming rarely have a background in special education or other disability-related fields (Vogel et al., 2006). A lack of support for their child's needs has been cited by parents of children with disabilities as a barrier for their child, and subsequently the whole family, to participate in faith-based settings (Ault et. al., 2013a). Additionally, a systematic review of the literature (Chapter 2) found that one of the top supports that people with disabilities need to support their participation in faith settings, is for disability education and training to be provided to those in the faith community (Miller & Skubik-Peplaski, 2020).

Furthermore, this researcher conducted a previous study with children's volunteers in faith-based settings to understand their experiences when working with children with disabilities (Chapter 5). The aforementioned study highlighted that many volunteers felt unequipped or found it difficult to handle the challenges of including children with disabilities in their setting. Additionally, while those interviewed overwhelmingly believed that children with disabilities should be fully included in their setting, most stated that their current programming was unable to completely accommodate the needs of children with disabilities. Lastly, volunteers in Chapter five's study unanimously discussed the need for training in order to support children with disabilities in their faith setting.

Supporting volunteers that work with kids with disabilities in faith settings is an important endeavor but currently there is very limited evidence in how to effectively do so. As of the Fall 2021, only one study could be found which implemented an education-based intervention for faith-based volunteers who work with children with disabilities. Baggerman et al. (2015) found that a coaching program provided to faith-volunteers by special education personnel increased the use of effective teaching behaviors by the volunteers working with children with disabilities. Further research in ways to support the inclusion of children with disabilities by providing intervention at the volunteer level in faith settings is important.

6.1 Defining Social Inclusion

As mentioned in Chapter 4 of this dissertation, part of the difficulty with social inclusion research is defining the terms. The construct of social inclusion as defined by Simplican et al. (2015) is the basis of understanding for the idea of social inclusion in this study. In their ecological model of social inclusion, Simplican et al. (2015) defined social inclusion as constructed of two domains – interpersonal relationships and community participation. This study will investigate the construct of social inclusion by examining children with disabilities' participation and interpersonal relationships in a faith-based setting to determine if intervening at the volunteer level (through coaching) will impact the children's social inclusion.

6.2 Occupational Performance Coaching

As discussed in Chapter 3 of this dissertation, occupational performance coaching (OPC) is a coaching model used in the field of occupational therapy to equip adults to better support children with disabilities (Kraversky, 2019). In OPC, an occupational therapist meets with an adult (usually the parent of a child with a disability) to coach them on how to support the child with a disability.

In Chapter 3 a scoping review was completed on how OPC has been used in occupational therapy with adults to support the participation of children with disabilities. This review provided the basis of the coaching model used in the current study. It was found that in studies that demonstrated positive outcomes, OPC typically occurred on a weekly basis for about one hour per week between the occupational therapist and adult(s) for 10-12 sessions on average. Occupational performance coaching has demonstrated effectiveness with supporting children with disabilities through training the coached adults (Kessler & Graham, 2015; Kraversky, 2019). Occupational performance coaching has historically been used with parents of children with disabilities. Thus, utilizing OPC with community volunteers instead of parents to support children with disabilities was a novel approach with this study.

6.3 Objectives

The purpose of this study was to determine if an OPC intervention with faith volunteer(s) who work with children with disabilities will improve the social inclusion for children with disabilities in that setting. Using Simplican et al.'s (2015) definition of social inclusion, the children's participation and interpersonal relationships were observed, thus the following two aims were addressed:

- Aim 1) Do children with a disability's participation in a faith-based setting increase after an OPC intervention has been implemented with volunteers in that setting?
- Aim 2) Do children with a disability demonstrate an increase in their interpersonal relationships with their peers in a faith-based setting after an OPC intervention has been implemented with the volunteers in that setting?

6.4 Methods

The effectiveness of the OPC intervention was examined from several different perspectives using a concurrent convergent mixed methods approach with repeated measures using a cohort design. Social network analysis was used to measure a child's interpersonal relationships, or social interaction, during classroom activities (Chapter 4). Goal Attainment Scaling (GAS; Kiresuk & Sherman, 1968) was used to assess a child's level of participation in the faith-based setting. Finally, the Canadian Occupational Performance Measure (COPM; Law et al., 2014) was used to measure the perceived performance and satisfaction of the adult volunteers of the study. Data from all outcomes were triangulated and analyzed in addition to field notes kept by the researcher to determine if an OPC intervention with volunteers increased the social inclusion for children with disabilities in faith-based settings. See Figure 1 for how the construct of social inclusion was measured using the two components as described by Simplican et al. (2015).

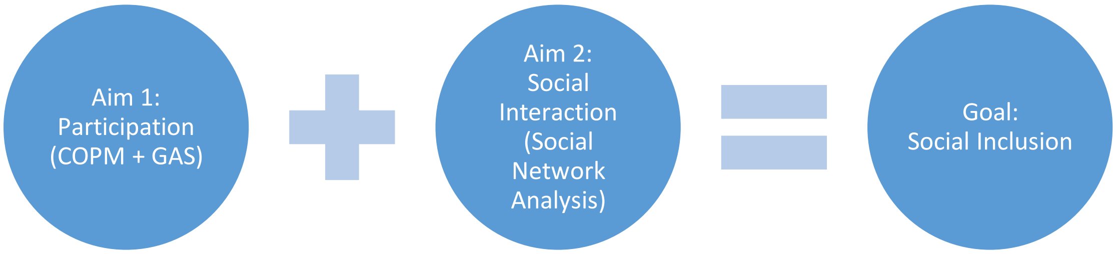


Figure 6.1: Social Inclusion Proposed Measurement

6.4.1 Recruitment

Faith settings within 150 miles of the researcher’s location (Cincinnati, Ohio) were contacted through various means (phone calls, email, private messages) to determine if their children’s program might be interested in participating in a study about increasing social inclusion for children with disabilities in their setting. Contact information for faith settings within the targeted area came from publicly available sources of information (such as websites, directories, and social media).

Once a faith-setting was identified with adult volunteers who were willing to participate, families within the faith setting were given a recruitment flyer from the faith setting which was created by the researcher. Interested families were able to contact the researcher over the phone, email or in person and set up a time to be screened for inclusion in the study. Recruitment occurred from April-August of 2021 and the availability of faith settings that met inclusion criteria of the study was significantly impacted due to ongoing COVID-19 limitations. Several church leaders indicated interest in participating in the study but noted their adult volunteers and the attendance of the children in their programs had been severely reduced due to the ongoing pandemic.

6.4.1.1 Inclusion Criteria

The population of interest for this study included one children's classroom in a faith setting that contained at least one adult (aged 18+) volunteer leader and five to twenty-five school-aged children (ages 6-17) that regularly participated (at least twice per month) in that programming. To measure the construct of interest, the researcher wanted two-to-five school-aged children (ages 6-17) with a diagnosed disability (such as Autism, Attention Deficit Hyperactivity Disorder, Down syndrome, cerebral palsy, learning disabilities, etc.) who regularly participated in their children's programming and at least three or more children without disabilities as part of the same classroom. No participants were excluded based on race, sex, or type of disability.

6.4.2 Study Participants

A purposive sampling of one "classroom" in the children's programming of a faith-based setting was utilized for this study. The faith-based setting was an Evangelical Free Church of America Church located in the Cincinnati, Ohio area. The church had an average Sunday morning attendance of 350-400 people, including about 75-100 children.

The classroom that was selected was a children's second-to-third grade classroom in a church that contained two adult volunteers and thirteen total children. It was pertinent to the study that at least two of the children in the classroom had an identified disability. One child had an autism spectrum disorder while the other child had a learning disability. No other identified disabilities were present within the classroom. The children's pastor, adult volunteers and child participants were all unknown to the primary investigator (PI) at the time of recruitment. Pseudonyms for all participants are used throughout this paper to protect anonymity. Kaleb and Trevor are the pseudonyms given to the two children with a disability.

The faith volunteers that led the classroom and who underwent the OPC intervention were the primary participants in the study. The two faith volunteers were a married couple that had been volunteering weekly in the children's ministry for several years. The children in the classroom were also participants of the study. Social network data was collected from all children in the classroom that consented so that the social networks of the children with disabilities could be compared to the social networks of the children without disabilities in the classroom. See Table 1 below for information on which participants were involved in which aspects of the study.

Table 6.1: Information about which parts of the studies the participants took part in

Participants	Adult volunteers in the classroom	Children in the classroom with and without disabilities
Intervention Provided by Researcher	Weekly 1-hour OPC by the occupational therapist for 10 weeks	None
Data Collected	Goal Attainment Scale (GAS) Canadian Occupational Performance Measure (COPM) *(Aim 1)*	Social Network Analysis Surveys *(Aim 2)*

6.4.2.1 Consent/Assent Procedures

This study received University Institutional Review Board (IRB) approval in the Spring of 2021 and all participant safeguard procedures were followed. Participant consent from the adult volunteers, parental consent from the parents of the children in the classroom and assent was all received prior to the start of the study. Parental consent and assent from the child was received by 84% (11/13) of the children that were considered "regulars" in the classroom (children that attended at least twice per month). Occasionally a visiting child would attend the classroom or children from other classrooms would be combined with this classroom due to COVID-19 interruptions, but those other children were not considered "regulars" and thus were excluded from recruitment and data collection. The two children who did not consent to the study were excluded from the social network analysis surveys.

6.4.3 Intervention

The intervention, OPC, was conducted following a protocol based on the scoping review conducted in Chapter 3 of this dissertation. Foundational studies on OPC conducted by Anaby et al. (2016); Dunn et al., (2012); Graham et al. (2010); and Graham et al. (2013) were used to determine the format and protocol of the coaching intervention. Additionally, OPC principles described in Kraversky (2019) were followed as well. The OPC intervention consisted of the researcher meeting with the adult participants of the study once per week outside of the children's programming time, for about 1 hour each session for a total of 10 sessions. The OPC sessions took place online via Zoom Software (Zoom Video Communications Inc., 2020). Each session included the following structured process based on the previously mentioned articles and the scoping review conducted in Chapter 3:

- Check performance/reflect on how the previous week(s) went
- Discuss goals and progress towards goals
- Explore options together to overcoming identified barriers to participation and inclusion for the children with disabilities
- Plan actions together (including the therapist providing evidence-based strategies to support the child)

See appendix A for an outline of the coaching sessions and topics that were addressed each week based on the feedback from the volunteers.

6.4.4 Data Collection

Following the guidance from the scoping review conducted on OPC in Chapter 3, the following outcome measures were used in this study: COPM, GAS, and social network analysis. According to the scoping review, most studies which evaluated the effectiveness of OPC used the COPM and GAS as outcome measures as well as an additional measure for the construct of interest. For this study, social network analysis was used to analyze interpersonal relationships. Data was collected throughout the study as reported in Table 2 and follow-up data was collected at approximately 3-weeks post-intervention to determine if any effects were sustained after the intervention.

6.4.4.1 Social Network Analysis Survey

Social network analysis surveys were utilized to collect data from all participating children in the classroom. Eighty-four percent of the regular children in the classroom agreed to participate in the study. In social network analysis research, a sample of at least 80% of a given bound sample is considered ideal and sufficient (Brass, 2021). Social network analysis surveys were collected from each child participant (children with and without disabilities) to understand how much a child with a disability interacted with peers in his or her faith program compared to their non-disabled peers and how that may be impacted by an OPC intervention. Social inclusion was measured by using the social network analysis principles of centrality as well as looking at the overall network makeup of the children with a disability compared to the children without disabilities (as presented in Chapter 4).

Social network data was conducted via a short 4-question survey which was deployed approximately every two weeks to gather change over time. Social network data was also collected at the follow-up phase to determine if any increases in degree of inclusion persisted after the intervention. This survey took less than 5 minutes per child participant. To assist the children with answering the questions, a written roster of names of children was provided to the classroom. Children were allowed to write as many names as they wanted per question, there was no minimum or maximum. The questions on the social network survey are detailed below:

1) Who do you like to spend time with inside this classroom?
2) Who would you spend time with outside of this classroom?
3) Who did you spend time with today?
4) Who would you like to spend time with in the future?

The timeline of administration of the survey throughout the study was based on the guidance of the LINKS Center for Social Network Analysis at the University of Kentucky. The survey questions were developed based on the research by Mamas et al. (2019), which provides details on how to conduct social network analysis within classrooms to measure social interactions between students with and without disabilities.

Guidance from an Associate Professor of the LINKS Social Network Analysis Center at the University of Kentucky was also utilized in the development of the survey questions.

The social network composition of the children which is displayed as a diagram, called a sociogram, as well as the individual children's centrality (a well-established social network analysis construct detailed in Chapter 4) was analyzed using social network analysis software UCINET (Borgatti et al., 2002) and NetDraw (Borgatti, 2002). The social networks of the children with disabilities were compared to those of the children without disabilities. Social network analysis was used to measure a child's level of social interaction with others in the classroom and was used in conjunction with measures of participation (GAS and COPM) to assess one's level of social inclusion in the classroom.

6.4.4.2 Goal Attainment Scaling

Goal Attainment Scaling is used to measure constructs that may not have an existing standardized way to measure and is used in a variety of contexts with a many different populations (Krasny-Pacini et al., 2016). It consists of creating scaffolded goals to measure progress towards a targeted outcome. When creating a GAS, the goals are set with the client, thus content validity of the GAS is considered to be high. Goal Attainment Scaling is frequently used in rehabilitation interventions because of its responsiveness to assessing change (Krasny-Pacini et al., 2016). Some studies have demonstrated GAS to have high reliability and Krasny-Pacini et al. (2016) provided specific criteria for researchers and clinicians to improve the reliability of GAS. Once a GAS has been created, it takes approximately 3-5 minutes to administer.

Goal Attainment Scaling was used in this study to measure how a child with disability's participation in their faith setting changed during an OPC intervention. How the child's participation was defined was individualized and determined in the initial goal setting session with the researcher and adult volunteers of the study. A GAS was created for each child with a disability that participated in the study and was re-assessed at weeks four, eight, and eleven, and at a three-week follow up post-intervention (week 14).

6.4.4.3 Canadian Occupational Performance Measure

The COPM assesses performance and satisfaction on individually identified areas from a client (COPM, n.d.). The COPM has demonstrated good reliability and validity and good responsiveness to change and is considered to be very client-centered (COPM, n.d.). A change of 2 points in either category (performance or satisfaction) when re-testing is considered a clinically significant change (COPM, n.d.). Administration of the COPM takes approximately 15-30 minutes to complete.

The COPM was administered to the two adult volunteers in the classroom to gauge areas of concern for the classroom as whole which they felt made participation for the children with disabilities difficult. The volunteers came to a consensus on the targeted areas they wanted to improve and provided numerical ratings in the categories of performance and satisfaction for the identified targeted areas, as per the COPM administration guidelines. Consensus was also reached on all of the numerical ratings obtained. The COPM was conducted at baseline, at week 11 of the study (originally supposed to be week 10 but was extended by one week due to COVID-19 limitations) and then 3 weeks after the intervention (week 14). The COPM was used to guide the discussions during the OPC sessions.

6.4.4.4 Triangulation of Data

The COPM and GAS helped to measure the participation component of social inclusion, while social network analysis measured the interpersonal relationship component of social inclusion. Additionally, unobtrusive field observations occurred by the primary researcher in the classroom during the regularly scheduled children's programming for 90 minutes every week (except for one week due to COVID-19 limitations) during the 10-week intervention phase of the study. Field notes were taken during these observations to help with data analysis as well as to help with the reflection component of the OPC sessions. Field notes were also taken during the coaching sessions with the adult volunteers for the investigator to be able to reflect throughout the study.

6.4.5 Trustworthiness

In order to increase the rigor of the results of this study, several precautions were taken to increase trustworthiness following guidance from Creswell and Poth (2018). The PI of the study used a reflexivity journal throughout the duration of the study to help examine and manage any biases that may have impacted the data or the interpretation of the data. Additionally, this study used triangulation of multiple data sources to help validate the results. The way the COPM and GAS were conducted with the adult volunteers in the study allowed for member-checking. Lastly, engaging in prolonged observations while keeping field notes with thick, rich descriptions during the observation sessions and coaching sessions to help with interpretation and analysis.

6.4.6 Study Timeline

The study timeline as it was completed for this study can be found in Appendix B. Originally the intervention phase was set to last weekly for 10 weeks with a follow-up at 4 weeks post-intervention. However, on the 10th week, only two children were in attendance of church (due to Fall break and many families being out of town) so social network data collection and the coaching session for that week were moved out to the following week. Follow-up occurred on the originally scheduled end date which ended up being 3 weeks post-intervention. A number of children were absent at the 3-week follow-up due to illness. Another attempt was made for a 4-week follow up one-week later, but even more children were absent (including both children with disabilities).

Table 6.2: Visual representation of what study activities occurred when. Grey boxes note activities completed with the adult volunteers, black notes activities completed with the child participants, and X's are to indicate the dates the PI completed observations.

Week	1	2	3	4	5	6	7	8	9	10	11	12	13	14
OPC Intervention	▨	▨	▨	▨	▨	▨	▨	▨	▨	Missed due to multiple absences	▨			▨ Follow-up
Classroom Observations	X		X	X	X	X	X	X	X		X			X
GAS	▨			▨				▨			▨			▨
COPM	▨										▨			▨
SNA Survey	■		■		■		■				■			■

6.4.7 Data Analysis

Changes in the GAS and COPM scores were reported in table form to help facilitate a descriptive analysis. Social network analysis data (centrality) was calculated using the UCINET Social Network Analysis software (Borgatti et al., 2002). Sociometries were created by the NetDraw software (Borgatti, 2002) and were examined to determine the social network analysis results. Descriptive statistics and paired-samples t-tests were conducted with the centrality data to determine the significance of results.

6.5 Results

In accordance with the Simplican et al. (2015) construct of social inclusion, measures of participation (GAS and COPM) were used in conjunction with social network analysis to assess the social interaction component of social inclusion. This study used a mixed methods design to triangulate the constructs of social inclusion (participation and social interaction).

6.5.1 Aim 1: Participation

6.5.1.1 COPM

For the COPM, a change in +2 in either the Performance or Satisfaction calculated total scores are considered “clinically significant” (Law et al., 2014). See Table 3 below for the areas of concern identified by the volunteers for the class as a whole and their rated performance and satisfaction scores at the different time points in the study. The total performance and satisfaction scores are reported as the average of the top five areas of concern, based on the administration guidelines of the COPM (Law et al., 2014). An increase of +3.2 in performance and +3.6 in satisfaction occurred at the 11-week re-assessment from the initial assessment. At follow-up those changes were sustained, and satisfaction increased by an additional + 0.4 point, demonstrating clinically significant positive changes for the classroom as a whole in the study.

6.3: COPM Scores

	Initial		11-Week Re-administration		14-Weeks (3 week follow-up)	
	Performance (Perf.)	*Satisfaction (Satis.)*	*Perf.*	*Satis.*	*Perf.*	*Satis.*
Kids shutting down and not participating	2	2.5	9	10	10	10
Kids getting loud and out of control	6	6.5	8	8	7	9
Kids talking when they should be listening	6	5	7.5	8	7	9
Kids sitting down and listening	9	10	8	9	8.5	9
Parent pick-up going smoothly	2.5	3	9	10	9	10
TOTAL (average of 5 areas)	5.1	5.4	8.3	9	8.3	9.4
Change from baseline:			**+3.2**	**+3.6**	**+3.2**	**+4.0**

6.5.1.2 GAS

For the two children participants with disabilities in this study, a more individual approach was used to examine their participation in the classroom. A GAS was created individually for each child with a disability and re-assessed at weeks four, eight, eleven and fourteen. The goals determined to use for the GAS were decided by the adult volunteers of the study with minimal guidance from the PI. The initial GAS score for both children on their individualized goals was a (-2) which is consistent with the baseline criteria for how the GAS is structured (Kiresuk & Sherman, 1968). The targeted goal for a GAS is assigned a value of 0 and a value of +1 or +2 is considered surpassing the targeted goal. Both children with disabilities received a +1 score at week 11 and at the

3 week follow up at week 14 as seen in Figure 2. The GAS for the children with disabilities can be found in Table 4 below.

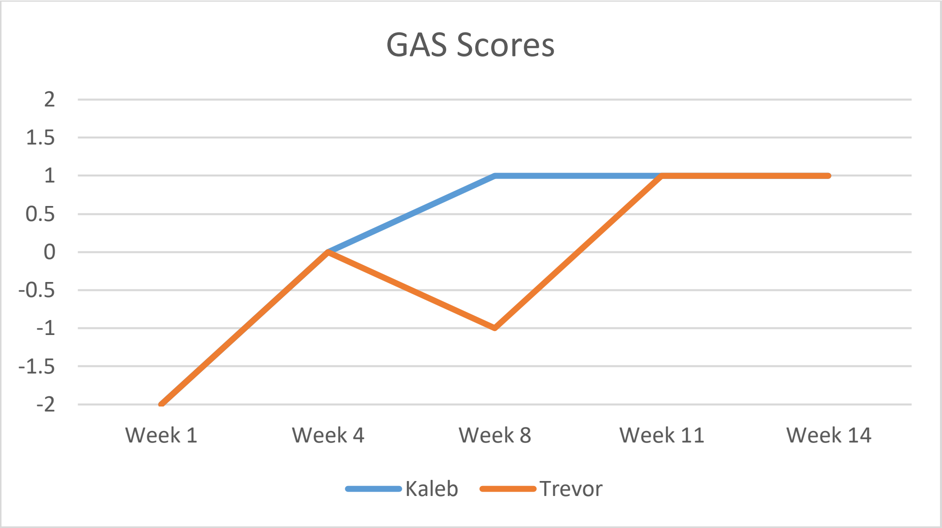


Figure 6.2: Goal Attainment Scores for both children with disabilities

Table 6.4: Goal Attainment Scales for the children with a disability

GAS Rating	**Kaleb**	**Trevor**
+2	Child greets others unprompted or otherwise seems excited to enter classroom, is engaged and encourages other children to participate	Child invites others to play during free play
+1	Child greets others unprompted or seems excited to enter classroom and participates (such as answering questions) well in activities	Child is willing to interact with others during free time without encouragement needed.
0	Child willingly comes to the classroom and participates in activities (such as answering questions)	Child is generally willing (with minimal encouragement) to interact with others during free time
-1	Child either willingly comes to the classroom and does not participate, or participates in classroom activities but remains nervous/secluded at times.	Child is willing to interact with others (not same children) during free time but needs a lot of prompting/ encouragement
-2	Child is generally nervous/secluded upon coming to class and is minimally engaged in classroom activities	Child generally interacts with same people every time during free play

6.5.2 Aim 2: Social Interaction

The social network analysis surveys were administered to all children present in the classroom at six time points: five times during the intervention phase and once at the week 14 follow up. The surveys were analyzed and the children with disabilities' centrality in relationship to the entire classroom was calculated for each question at each assessed time point. Table 5 demonstrates the children with disability's mean centrality scores.

Descriptive and inferential statistics were used to compare the mean of the children with disabilities' centrality to the rest of the group's centrality for each question across all weeks. A p-value of ≤.05 was used to determine significance. An independent t-test showed that Kaleb demonstrated decreased centrality overall compared to his non-disabled peers with regards to question 1 (p=.03), question 2 (p =.05) and question 4 (p =.05) which will be further discussed below. Trevor demonstrated above average centrality compared to his non-disabled peers on all questions of the SNA survey, but none of which were statistically significant. Lastly, paired samples t-tests were conducted for the two children with a disability to evaluate the change in centrality over time. The statistical tests demonstrated there was no significant increase in the centrality of either individual over time. However, it was noted that even though Trevor was absent the last week of data collection, others in the class still listed him on the survey as someone they like to spend time with, someone they would like to spend time with outside of the classroom and someone they would like to spend time with more in the future.

Table 6.5: Centrality Scores of the children with disabilities compared to the children without disabilities. P-value for statistical comparison for children with disabilities to children without disabilities in parenthesis. A zero indicates no nominations from or to the child were recorded.

	Kaleb's centrality (Mean)	**Trevor's centrality (Mean)**	**Non-disabled peers' centrality (Mean)**
Question 1	0 (p= .03)	1.34 (p=.27)	.79
Question 2	0 (p=.05)	1.17 (p= .28)	.55
Question 3	1.17 (p=.32)	1 (p= .65)	.72
Question 4	.17(p=.05)	.71 (p= .64)	.67

Each sociogram was visually analyzed and compared to gather more information about the social interactions the children in the classroom reported each week. Of particular interest were the results of question three of the social network analysis survey, which asked each child who they interacted with that day. The results of the sociograms as created by the NetDraw software (Borgatti, 2002) for question three of each week data was collected (weeks 1, 3, 5, 7, 11, and 14) can be found in Figures 6.3-6.8 below. The children with disabilities are highlighted by red nodes and the children without disabilities are highlighted by blue nodes. Adult volunteers in the classroom are highlighted by yellow nodes. Individuals who have an "X" by their name indicates they were absent on that day of data collection. Pseudonyms are also used in the sociograms for participant anonymity.

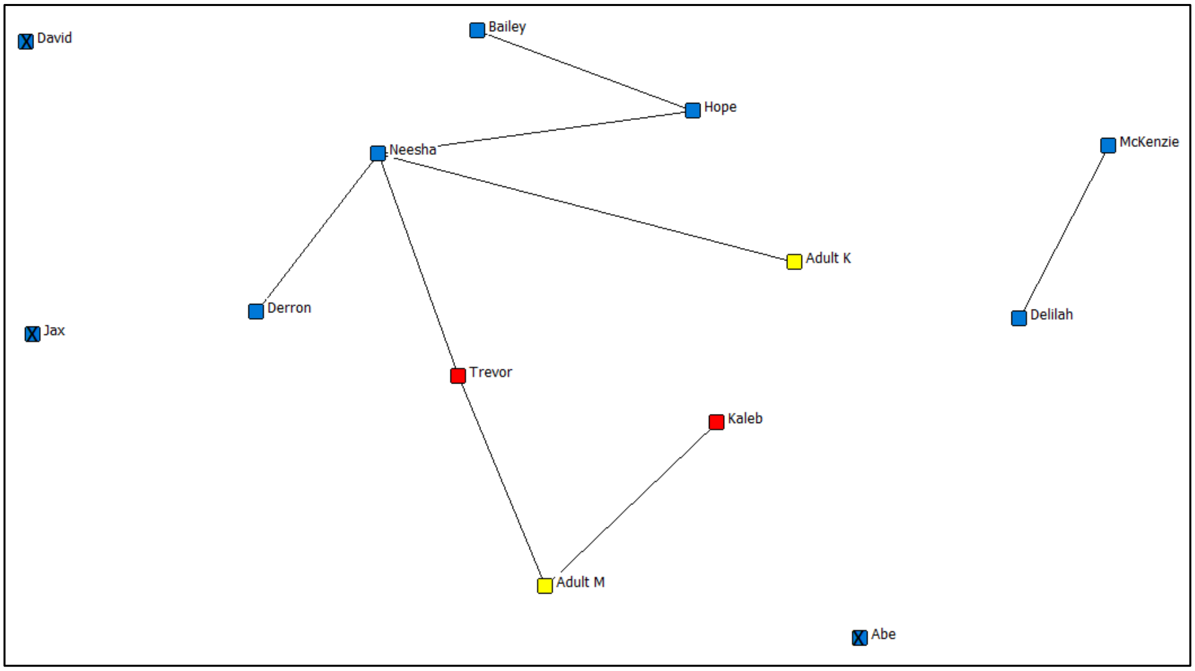


Figure 6.3: Week 1 Question 3 Social Network Survey Sociogram

In week 1 (Figure 3) the two children with disabilities listed an adult volunteer in the room as someone they interacted with and only one of the children with a disability (Trevor) indicated one peer in the room as someone he interacted with that day.

In Week 3 (Figure 4), there was very low attendance as noted by the sociogram. In week 3, Kaleb only listed adults as individuals he interacted with, and the only other child in attendance that day, Jax, did not list Kaleb as someone he interacted with.

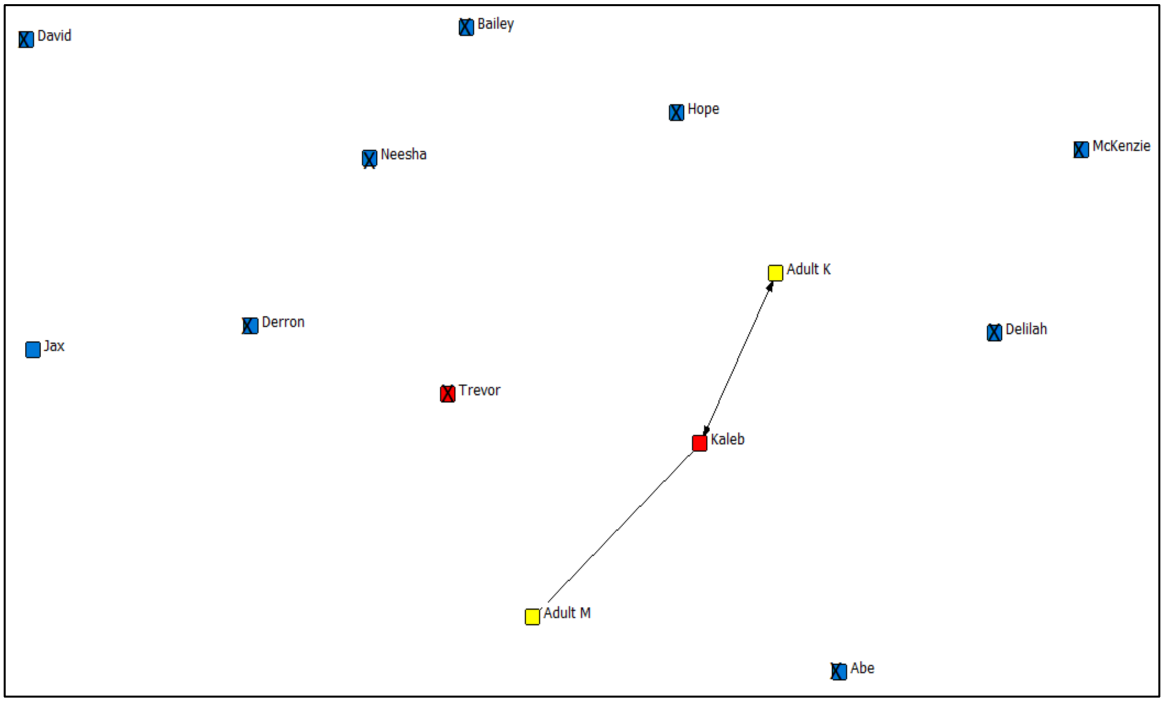


Figure 6.4: Week 3 Question 3 Social Network Survey Sociogram

In week five (Figure 5), there was a change in the individuals listed as having interacted with both of the children with disabilities. No longer were the adult volunteers in the room listed, but instead, peers were. Additionally, Kaleb interacted with two peers and Trevor was listed as interacting with three peers that day, both an increase from week 1 (Figure 3).

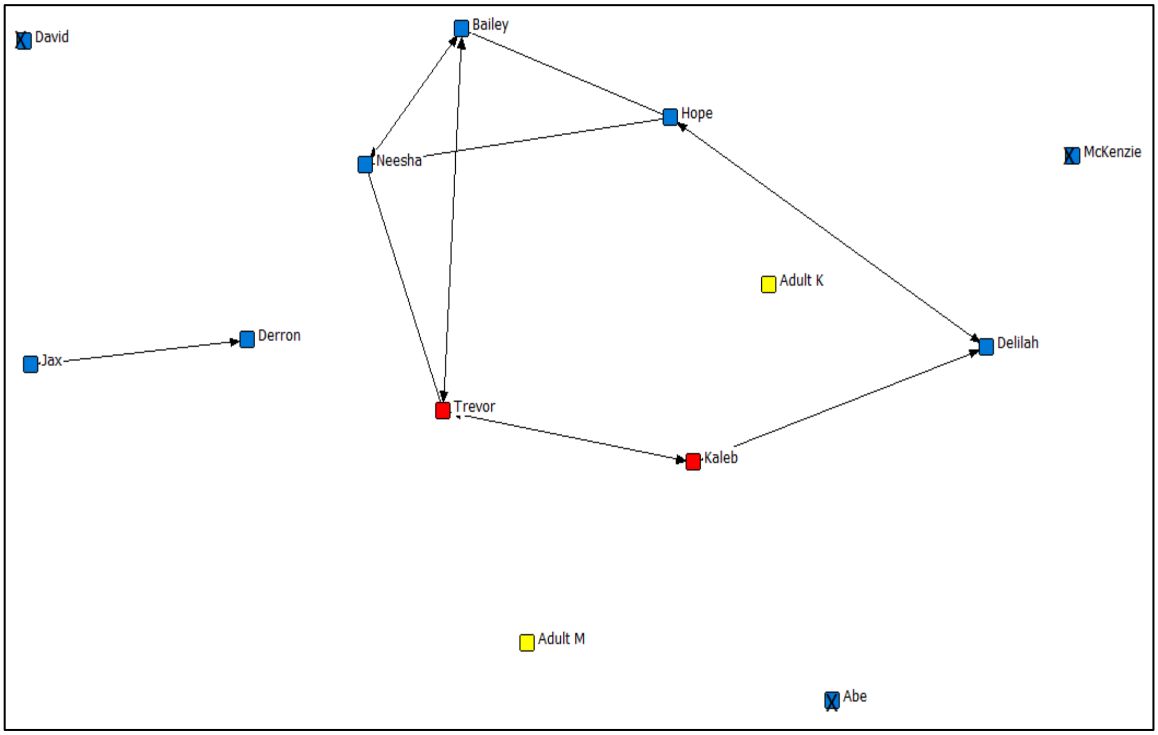


Figure 6.5: Week 5 Question 3 Social Network Survey Sociogram

In Week 7 (Figure 6.6) it is noted that both Trevor and Kaleb no longer listed the adult volunteers in the room as who they interacted with during the day but instead listed their peers. However, both children with disabilities appeared to only interact with one other peer on this date. It is noted though that the other children that Kaleb and Trevor interacted with on week 7 were different from previous weeks.

In weeks 11 and 14 (Figures 6.7 and 6.8, respectively) there were significant absences in the room due to illness which made analysis difficult, however it is noted that even with less peers available, Kaleb no longer listed one of the adults in the room as a person he interacted with during the day.

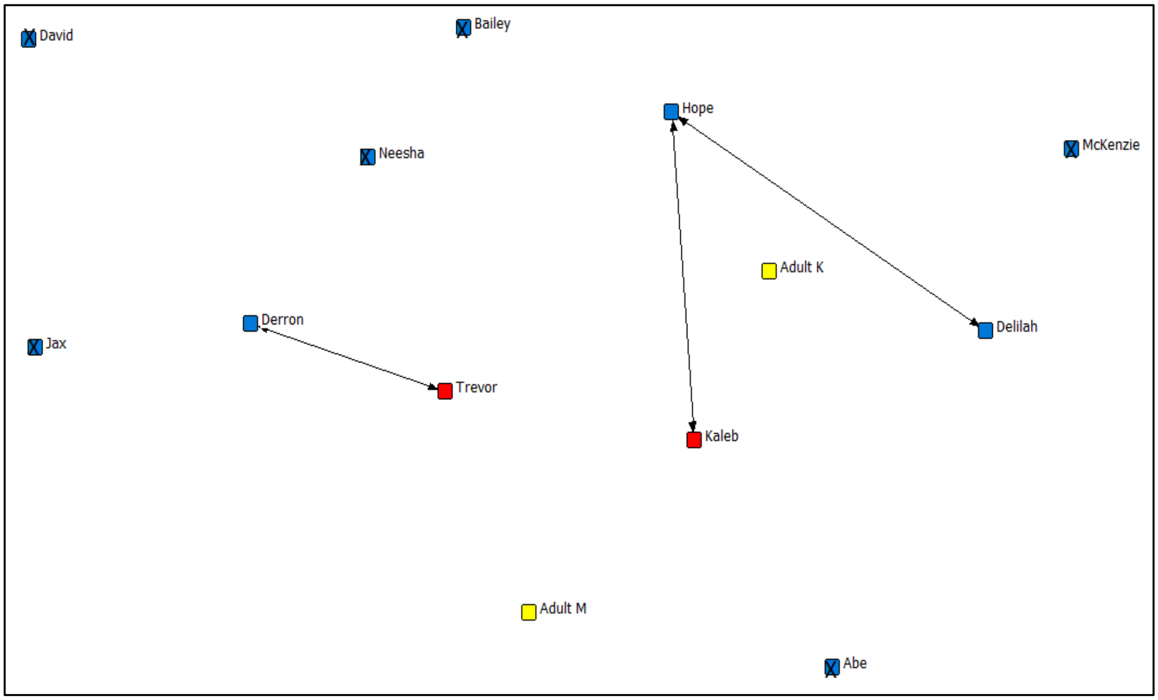


Figure 6.6: Week 7 Question 3 Social Network Survey Sociogram

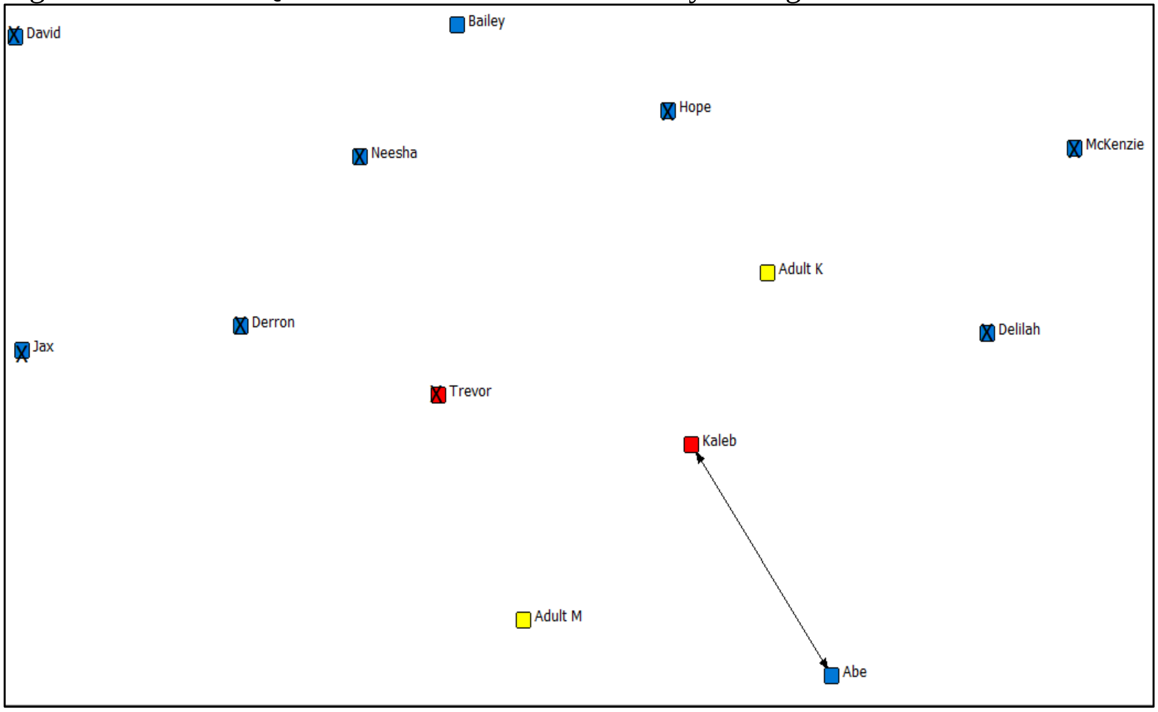


Figure 6.7: Week 11 Question 3 Social Network Survey Sociogram

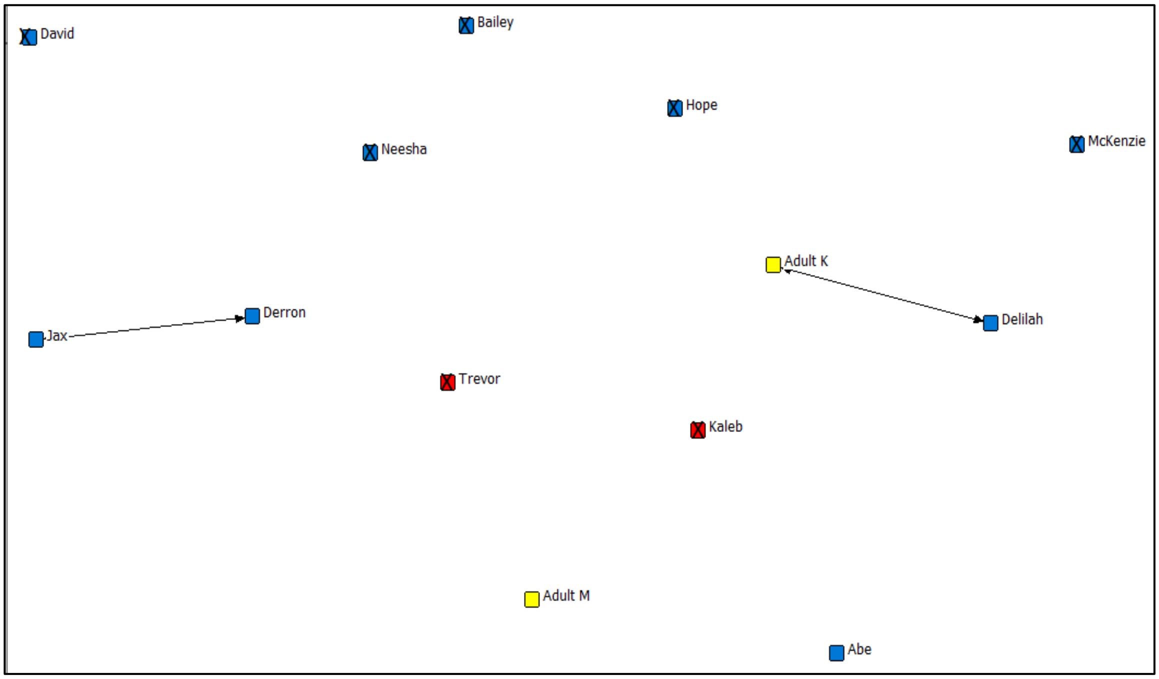


Figure 6.8: Week 14 Question 3 Social Network Survey Sociogram

6.5.2.1 Additional Results:

Field notes were recorded during the observations in the study as well as during the OPC sessions with the adult volunteers. The field notes indicated that both Kaleb and Trevor over time appeared to participate more in the classroom activities. At the beginning of the study, Kaleb would often be reserved and did not interact much with his peers. However, towards the end of the OPC intervention, Kaleb initiated more interactions with his peers and his peers interacted more with him. Trevor interacted more with his peers prior to the OPC compared to Kaleb but generally only interacted with the same two peers and had a difficult time participating at times due to some outbursts he would have. It was noted that as the OPC intervention went on, Trevor's outbursts decreased, he followed the rules/directions in the classroom more consistently and interacted more with other peers in the room.

In addition to the COPM data, the adult volunteers noted they felt more comfortable and confident with working with kids with disabilities. Adult K reported developing a passion for kids with disabilities and wished more kids with disabilities would come to their church, and that more volunteers would develop a similar passion for supporting kids with disabilities. During one OPC session, adult K discussed an instance when a child was demonstrating significant negative behaviors during a classroom session. They noted "I felt like I was using my tools"- indicating they felt they were transferring the skills gained during the OPC intervention to other situations.

Another thing that is important to note is that during the study timeframe, a number of other events and activities occurred as a result of the researcher's input and presence within the church. Table 6 below highlights additional activities that occurred as a result of this study.

Table 6.6: Additional activities that occurred as a result of this study

Activity	**PI's Involvement**
Training: Disability training initiated for children's volunteers on all church campuses	PI was asked to co-lead training with one of the campus pastors
Respite Night: Church hosted their first respite night for families with children with disabilities – over 20 families and 50 volunteers participated	PI assisted with the planning and execution of the evening; a church member led the event
Disability Awareness Sunday Church plans to hold a "Disability Awareness Sunday" in Spring 2022	PI was asked to help plan and execute with the Children's Pastor
Training: Church plans to hold an additional, more in-depth disability training for children's volunteers	PI was asked to help plan and execute
Visual Schedules: All school-aged classrooms in the church are now using visual schedules	PI created the visual schedules; volunteers of the current study trained other volunteers to use
Consultation:	PI was asked to observe and provide suggestions and

Church asked for more assistance/guidance with a younger child with destructive behaviors in another room	support to the volunteers in that classroom
Education: During one of the quarterly meetings with the children’s volunteers, the adult volunteers of this study were asked to share their experiences	PI attended the meeting
Podcast: The campus pastor of the church decided to address an episode of his podcast on disability and spirituality	None

6.6 Discussion

This study sought to determine if an OPC intervention for adult volunteers in a faith setting would impact the social inclusion of children with disabilities in that setting. It was hypothesized that through OPC, the children with a disability would be able to better participate in the faith-based programming and be more socially included. This study yielded several important pieces of information related to the inclusion of children with disabilities in faith-based settings. Each finding will be further discussed in a separate section below.

6.6.1 Impact of Occupational Performance Coaching on Social Inclusion

First, this study demonstrated that OPC was effective at increasing the social inclusion for children with disabilities in a community setting. Using Simplican et al.’s definition (2015) of social inclusion, each component is discussed below.

6.6.1.1 Impacts on Participation

Based on the GAS as one of the primary measures of participation for both children with disabilities, the OPC intervention increased their participation in the faith-based setting. Furthermore, the gains in participation persisted at a follow-up assessment.

While OPC has not been reportedly used with adults outside of parents of children with disabilities, the findings of this study are consistent with other studies using OPC as an intervention to increase participation (Graham et al., 2010; Graham et al., 2013; Pashazadeh Azari et al., 2019; Suja Angelin et al., 2021). Additionally, based on using the COPM as a measure of participation for the class as a whole, the areas that the adult volunteers noted as barriers for participation all improved to the level of clinical significance. Adult volunteers noted an increase in performance and satisfaction in COPM scores that were also maintained at follow-up testing. These findings are also consistent with other studies which have used OPC as an intervention and the COPM as an outcome measure (Graham et al., 2010; Graham et al., 2013; Pashazadeh Azari et al., 2019; Suja Angelin et al., 2021). Overall, these findings demonstrate the OPC intervention was successful in increasing the participation of children with disabilities in the faith-based setting.

6.6.1.2 Impacts on Social Interaction

When examining the social network analysis data, although nothing statistically meaningful changed with the social interaction component, there were some promising trends for the children with disabilities. One of the most promising pieces of data that emerged from the social network data was that by the end of the study, the children with disabilities no longer listed the adults in the room as the people they “interacted” with and instead listed their peers. Kasari et al. (2011) and van Asselt-Goverts (2015) both found that individuals with disabilities tend to have less peers in their social networks compared to non-disabled individuals. Kaleb demonstrated this concept as his centrality scores were lower compared to his peers. Additionally at the beginning of the study Kaleb mostly listed the adults in the room as individuals he interacted with instead of peers. As the OPC intervention went on peers nominated Trevor for things even when he was absent. The present study shows that with an OPC intervention, the social network composition of a child with a disability may shift to include less adults and more peers in an individual's network.

It is notable that this study took place during the Fall of 2021 during the Delta wave of the COVID pandemic. While centrality would be a good way to measure social interaction within a bound social network, the numbers reported in this study need to be interpreted in light of the fact that attendance in the classroom was much more variable than usual (according to the adult volunteers and children's pastor of the church). As such, while Trevor's centrality score was "higher" than average compared to the rest of the peer group, his and Kaleb's attendance was also much more consistent compared to the rest of the peers in the classroom. The lack of consistent attendance by the non-disabled participants in the classroom almost certainly impacted the overall centrality of the room negatively and this needs to be considered in the interpretation of these results.

It is hypothesized that in a group with more consistent attendance, the differences in centrality between individuals with and without disabilities, and the changes in centrality over time would be more notable. Chamberlain et al. (2007) noted that when a child with a disability was more on the periphery (less centralized) of a social network in a classroom, they reported lower levels of feeling accepted and lower companionship. Thus continuing to examine centrality in community settings and its impacts on children with disabilities is important to understand the social impacts of interventions like OPC.

There are several possible explanations for why the children with a disability interacted more with their peers as the study timeline went on. One possible explanation is that the children with disabilities were able to participate in the classroom activities more due to the small changes the adult volunteers made to the environment and the activities. The ability to participate more, likely allowed the students with disabilities to follow more of the social mores of the classroom structure, thereby helping them to assimilate with their peers a bit more.

Another explanation for why the children with disabilities interacted more with their peers as the study went on may have been because the culture of the room may have shifted. The PI noted several times in the field notes that the adult volunteers appeared to be more comfortable interacting with the children with disabilities. An increase in self-efficacy in working with children with disabilities has shown to increase attitudes of inclusive education in school-based educators (Savolainen, et al., 2020). Additionally, an increase in positive attitudes towards inclusion has shown to lead to more inclusive teaching practices in school-based personnel (Sharma & Sokal, 2016). As the adult volunteers of this study appeared to be more comfortable interacting with the children with disabilities, they may have modeled inclusive attitudes and behaviors for the other children in the room. This modeling of behaviors may have helped to normalize the children with disabilities to the rest of the children in the class.

Though the calculated centrality did not change significantly enough to demonstrate an increase in social interaction over time due to the OPC intervention, the change in network structure is enough to suggest some positive impacts on the social interaction of the children with disabilities.

6.6.1.3 Impact on Social Inclusion

Both children with disabilities in the study experienced increased participation and positive changes in their social interactions when an OPC intervention was utilized with the adult volunteers in the classroom. As participation and social interaction comprise the two constructs of social inclusion (Simplican et al., 2015), it is suggested that an OPC intervention used with adult volunteers does have positive impacts on the social inclusion of children with disabilities in faith-based settings.

6.6.2 Feasibility of Occupational Performance Coaching with Community Volunteers

A second novel component of this study was the application of an OPC model with community volunteers instead of parents, with the goal of supporting children with disabilities in community settings. Historically, inclusion interventions have focused on the child with a disability (Gibson et al., 2009). As noted in Chapter 3 of this study, coaching interventions for participation of children with disabilities have similarly been conducted only with the parents of a child with a disability. This approach that has been used over time puts the burden and responsibility to increase their own social inclusion on the child with a disability and their family (Koller & Stoddart, 2021).

Perpetually putting the responsibility for change on the individual with a disability and/or their family is likened to following the more traditional medical model approach, instead of a more progressive social model of disability (Gibson et al., 2009; Koller & Stoddart, 2021). Aldersey et al. (2017) discussed how often within a medical model of disability, parents of children with disabilities have to act as educators of others and advocates for their child with a disability in the community. This role as parent educator and advocate can cause additional stress on the family, additional burden on the family and can cause the families to feel that they are “troublemakers” and isolated (Aldersey et al. 2017). Simplican et al. (2015) discussed how a family’s community and the environments in which they operate can have profound roles in impacting social inclusion for individuals with disabilities and their families. By using a social model approach in community settings, such as faith-based settings, to intervene at the contextual level, more opportunities can be provided to the children with disabilities and their families to have more societal inclusion. The present study demonstrates that providing an OPC intervention to community volunteers is both a feasible and effective approach to support the social inclusion of children with disabilities in community settings without increasing the burden on parents and families that have children with disabilities.

6.6.3 A Catalyst for Change

An unexpected outcome of this study was the faith setting’s increased interest and engagement in the concept of supporting individuals with disabilities who attended the church. This is similar to Savolainen et al.’s, findings which showed that as individuals’ self-efficacy with providing support for individuals with disabilities increased, their use of inclusive practices increased as well (2020). Table 5 lists the notable activities that occurred as a result of this research study being conducted at the church. Many of the activities that occurred were also listed in Chapter 2 of this dissertation as supports that individuals with disabilities desired to increase their participation in faith settings. For example, providing training has been identified as a resource in previous literature (Ault et al., 2013a; Ault et al., 2013b; Carter et al., 2016; Hobbs et al., 2016) and training was requested by the church in this study. Providing supports outside of worship services, such as a respite night was mentioned in several studies (Ault et al., 2013a; Ault et al., 2013b; Carter et al., 2016); the church in this study initiated their first respite night with the assistance of the PI. Modifying services to increase participation was also mentioned in the systematic review (Chapter 2) and the church in this study requested the PI create visual schedules for all of the classrooms to help all students participate more successfully. Simply engaging this church in the study appeared to push them to action.

It appears the current study empowered not only the adult volunteers of the study, but the children's pastor and campus pastor and even those in the congregation not otherwise connected to the study to want to better include children with disabilities and their families. Further, the church has plans to continue trying to increase their inclusivity by doing things such as future trainings, future respite nights and future disability awareness events. Savolainen et al., (2020) found that as ones' self-efficacy with providing support to individuals with disabilities increases, their use of inclusive practices also increases; this finding was also supported by this study. One of the primary supports listed in the systematic review in Chapter 2 was that individuals with disabilities overwhelmingly wanted churches to have positive, welcoming attitudes towards those with disabilities. The shift seen church-wide as a result of this study and all of the activities that happened as related to this study seems to be a catalyst for change that will allow the church to be more welcoming and hopefully more inclusive towards those with disabilities in the future. This is an encouraging model for other churches to follow.

6.6.4 Strengths and Limitations

There are several strengths and limitations to this study. The researcher took actions to bolster the credibility, confirmability, and dependability of the findings.

Triangulation of data, prolonged observations, reflexivity and member checking were used.

The professional background and unique training of the PI was also an asset to this study. As a LEND graduate (Leadership Education in Neurodevelopmental and related Disabilities), the PI had already completed several years of research on community inclusion for individuals with disabilities. Additionally, the PI has received extensive training in Social Network Analysis through the LINKS social network analysis center at the University of Kentucky, two LINKS week-long summer workshops and one graduate level research SNA course.

Another strength to this study is that it supported the social inclusion of children with disabilities through the social model of disability- modifying the environment and tasks to facilitate the participation of children with disabilities instead of trying to fix the child with a disability. Historically interventions have been focused on “fixing” the child with a disability instead of modifying the environment and activities to better accommodate the needs of a child with a disability.

There were several limitations to this study, however. One of the biggest limitations was that the study was conducted during the COVID-19 pandemic which significantly impacted the availability of participants during both the recruitment and intervention phase of the study. Even with contacting churches within a large geographical range (150 miles of Cincinnati), it was difficult to find a church who was able (by meeting criteria) and willing to participate in the study. Some churches may have shied away from the ten-week commitment needed from the volunteers, thus researching to see if shorter coaching protocols are effective would be advantageous.

Other churches may have been hesitant to participate due to the ongoing global pandemic causing a lot of certainty in personnel within the church. Additionally, once a church was recruited, attendance within that site was less than what was originally desired. While variability of attendance in a community setting is expected more so than a setting such as a classroom in a school, the variability of attendance was even higher that what was expected, most likely due to the pandemic. Even though the majority of the children in the classroom consented and assented to participate in the study, the actual response rate of social network analysis data was much lower depending on the weekly attendance. If social network analysis is utilized in similar studies in the future, data collection would need to better account for this variability or find situations in which there is less variability across time.

An additional limitation to the study was the social network analysis questionnaire itself. While it was created following guidance from the LINKS center and previous SNA research, it was more robust than it needed to be for this study. Moving forward, the question on the survey that had the most pertinent information on it was question 3 – “Who did you interact with/spend time with today?” By decreasing the survey to only one question, any concerns of potential survey fatigue should be mitigated. Additionally, some of the participants had difficulty answering the questions that were more abstract (questions 1, 2, and 4). By eliminating those questions the survey would be that much easier for the children to complete.

This study focused on one classroom in one congregation and it occurred during a global pandemic. While the findings were positive, it is suggested this study be replicated with other cohorts and ages to determine the effectiveness and feasibility of OPC in faith-based settings where attendance may be more consistent. Finally, a limitation was that this research was conducted by a single researcher who had not used an OPC intervention prior to this study. While the researcher conducted a scoping review and did extensive research to develop a protocol for the intervention, the reliability of the intervention and conclusions must be interpreted with that information.

6.6.5 Implications

This study demonstrates that an OPC model is both feasible and effective as a way to improve the social inclusion of children with disabilities in faith-based settings. While an occupational therapist who is able to provide OPC may not be available to every faith-based setting that wants to increase inclusion for children with disabilities, it at least provides an avenue for a faith-based setting to explore. It has been encouraged previously that churches look within their own congregations to find expertise that may be able to help the church initiate changes to better support those with disabilities (Carter, 2016). This study is one example of a rehabilitation professional using their skills to support a church’s effort to increase inclusion for children with disabilities. Churches may want to look within their own congregation or at other connections they may have with professionals who may be able and willing to support their efforts to increase inclusion for people with disabilities.

6.6.6 Future Research

There are several directions for future research based on the current study. Future studies should confirm these results in other faith-based settings during non-pandemic times and with other age groups. Additionally, future research could expand the use of this model of OPC intervention to other community-based settings where there is regular and prolonged participation (such as scout troops, summer camps, and library programming). Other studies can focus on determining the most efficient model that provides successful results from an OPC intervention. In the scoping review conducted in Chapter 3, the study that limited the number of coaching sessions to four sessions total did not demonstrate sustained positive changes (Bulkeley et al., 2016). However, using some of the data above, recognizable positive changes were occurring by weeks 5 and 8. Therefore future research should determine if all 10 coaching sessions are necessary or if a shorter duration would be as effective. By shortening the duration of the coaching sessions, it may be a more feasible commitment for community-based volunteers who may be unable to commit to the full 10 weeks.

Future research could also use a similar design and add a qualitative component of interviews to confirm if the participants felt more socially included to increase the validity of using the SNA and GAS as measures of social inclusion. Finally, a follow-up study to assess the experiences of the adult volunteers as they went through this process to better understand what their experiences were like to determine if this is an approach that should be continued to use would be useful information.

6.6.7 Conclusion

Increasing social inclusion for those with disabilities in faith-based settings is an important endeavor that occupational therapists are uniquely poised to address. Steps to better measure social inclusion and interventions targeted at increasing social inclusion need to be further researched and refined to support the social inclusion of individuals with disabilities. It was discovered that an OPC intervention was a feasible and effective way to increase social inclusion in a faith-based setting. Occupational therapists and other rehabilitation professionals may be able to utilize an OPC model to support the social inclusion of children with disabilities.

CHAPTER 7. DISCUSSION AND CONCLUSIONS

In this dissertation, four studies with the ultimate focus on increasing social inclusion for children with disabilities in faith-based settings is discussed. Research is presented to better understand supports for participation for those with disabilities in faith settings, the experiences of adults who work with children with disabilities in children's programming in faith-based settings, and to determine if an occupational performance coaching (OPC) intervention with adult volunteers is effective at increasing the social inclusion of children with disabilities in faith-based settings. This chapter will recapitulate the results of these studies and discuss the implications of this research to faith-based settings as well as for rehabilitation practitioners. Future research on this topic will also be discussed.

7.1 Overview of Study Findings

Study 1. The first study, Chapter 2, was a systematic review which sought to better understand, from the perspective of those with disabilities, what supports were needed in faith-based settings to increase their participation (Miller & Skubik-Peplaski, 2020). There have been calls for several years to increase faith inclusion for those with disabilities in the church (Carter, 2016; Collins & Ault, 2010; Collins et al., 2001; Goldstein & Ault, 2015; McGee, 2010; Poston & Turnbull, 2004; Richie, 2015; Slocum, 2016). Prior to this review however, limited research was compiled from the perspectives of those with disabilities themselves (compared to the perspectives of church leadership and pastors for example). This review sought to follow the mantra "nothing about us without us" by elevating the voices of those with disabilities and their families instead of religious leaders which have largely been the participants of faith-based research. Individuals with disabilities and their families are one of the primary key stakeholders in this conversation about supports for participation but their voice has historically been left out of the research on faith-based inclusion.

While physical accessibility was a top-rated support in the literature, welcoming and supportive attitudes by individuals within the faith community were equally mentioned. Many faith-based settings may not be able to improve the physical accessibility of their churches due to structural and financial limitations. However, the desire for positive, welcoming attitudes in faith based settings echoes other literature on broader disability inclusion which overwhelmingly demonstrates the need for changed attitudes to remove the stigma and stereotypes that continue to persist and hinder inclusion efforts throughout society (Amado et al., 2011; Amado et al., 2012; Carter 2007; Carter, 2020; Goldstein & Ault, 2015; Hobbs et al., 2016; National Organization on Disability, 2005; Vogel et al., 2006). In addition to welcoming attitudes and physical accessibility, other supports were discussed in Chapter 2 including physical/ environmental accommodations as well as social-emotional accommodations faith-based settings can implement. Some of the suggestions may cost very little-to-nothing for a congregation to implement (such as offering roles for disabled participants to fulfill within the church).

The findings in this study indicate that there are some non-tangible and cost-free or low-cost ways that faith-based settings can work on increasing the participation of those with disabilities. The goal of this research was to highlight what needs to be implemented, from the perspective of those with disabilities, to help increase social inclusion in faith settings. Ault et. al (2021) demonstrated there is a disconnect in the views of church leadership/pastors and individuals with disabilities and their families about their perception on support for inclusion of people with disabilities in the church. Chapter 2 strives to provide a starting basis for congregations or rehabilitation practitioners involved in a church hoping to better support those with disabilities. Implications for professionals as well as faith-based settings were discussed.

Study 2. The second study in this dissertation was a scoping review to examine how OPC is utilized in the occupational therapy literature to support the participation of children with disabilities. Historically social inclusion interventions have been targeted at individuals with disabilities instead of the other factors that can also impact social inclusion (Gibson et al., 2009). Such other factors include the environmental contexts and activities in which the individual is participating (Gibson et al., 2009). Occupational performance coaching is a model in occupational therapy in which intervention is not conducted with the individual with a disability but with those supporting the individual with a disability so they are better equipped to understand and support the needs of the person with a disability. Occupational performance coaching aims to support the individual with disability's participation through changing the environment and the activities in which they participate in instead of "fixing" the person with a disability. Since this dissertation was focused on using the Social Model of Disability (Shakespeare, 2006) to guide strategies and interventions, the PI was interested at interventions targeted at the context, not the child with a disability in the faith settings. Occupational performance coaching is one such intervention that can provide environmental/contextual supports to increase the participation of those with disabilities (Kraversky, 2019).

The results of this study helped to create the OPC intervention protocol which was used in study four of this dissertation. Results of the scoping review indicated that OPC was the most used term in occupational therapy literature when talking about coaching others to support the performance of children with disabilities. Additionally, OPC models which demonstrated positive changes provided weekly OPC meetings with the coached adults for 10-12 sessions for about an hour each session. Outcome measures used to determine the effectiveness of OPC were also examined and reported and used to determine the outcomes used in study four. Other occupational therapists may find this literature useful when developing their own coaching protocols in occupational therapy.

Study 3. The third study in this dissertation was a phenomenological study which examined the experience of volunteers who work with children with disabilities in faith-based settings. In the literature there was an absence of understanding of these individuals' experiences when looking to better include children with disabilities in faith-based settings. The (often unpaid) volunteers are the ones directly providing the children's programming to all children in the faith setting, including children with disabilities who may attend. These volunteers rarely have any sort of formalized disability training or experiences with children with disabilities outside of their faith-based setting (Vogel et al., 2006). Furthermore, research has shown that many families with children with disabilities have left places of worship because their child with a disability was not adequately supported or welcomed (Ault et al., 2013a).

Study three highlighted that while the volunteers who were interviewed felt called to support the inclusion of children with disabilities in faith settings, they recognized that not all volunteers may feel that way. Additionally, the volunteers stated that they wanted more support in trying to better include children with disabilities in their faith settings and allow families to have a more normalized experience. Lastly, volunteers stated that there can be differing opinions or options on what including children with disabilities in their faith setting may look like. This study sought to close the gap between individuals with disabilities and the support they receive in their faith-based settings by understanding the front-line volunteers' experiences of working with children with disabilities in those settings. The information gained from this study helped to guide some of the topics in the the OPC intervention that was developed in study four to increase the social inclusion of children with disabilities in faith-based settings.

Study 4. The fourth study in this dissertation examined the effects of an OPC intervention with the goal to increase the social inclusion of children with disabilities in faith-based settings. The effectiveness of an OPC intervention directed towards volunteers in faith-based settings who work with children with disabilities was tested to see if it had an impact on the children with disabilities' social inclusion. Using guidance from the scoping review on OPC in Study 2 and information gained about the needs of volunteers in study 3, an OPC protocol was created. Weekly OPC sessions were provided by the PI (an occupational therapist) to adult volunteers of a children's classroom in a faith-setting for 10 weeks. During the coaching sessions, the PI and adult volunteers collaboratively reflected on the current state of social inclusion in the classroom for children with disabilities, discussed joint goals and together developed plans for increasing social inclusion for the children with disabilities in the study.

It was found that the OPC intervention increased the participation of children with disabilities in faith-based settings when measured using GAS and COPM. The OPC intervention also had an impact on the children's social interactions with others in that setting when examined from the lens of social network analysis. Thus, it was concluded that an OPC intervention can be both a feasible and effective approach when looking to increasing social inclusion for children with disabilities in community-based settings. To date, there is no published research utilizing an OPC intervention with adults other than parents or caregivers of individuals with disabilities to support the children with a disability, thus this is a novel approach with exciting future implications.

7.2 Implications for Practice and Connection to the Literature

Supporting everyday participation and inclusion for individuals with disabilities throughout society has become a legal if not mainstreamed effort since the signing of the Americans with Disabilities Act in 1990 (ADA.gov, n.d.). Yet there are still barriers to participation that individuals with disabilities experience daily. Occupational therapists are called to focus on the principle of occupational justice in which they strive to support individuals in participating in their desired occupations (AOTA, 2020). Promoting occupational justice is viewed as a way to create a more socially inclusive society and support the well-being of those with all types of abilities (Hocking, 2017). Finding ways to continue to promote daily participation and inclusion for individuals with disabilities is an important research undertaking.

One place where individuals, and particular to this dissertation, children with disabilities, continue to face barriers to social inclusion is in faith-based settings. Ault and colleagues (2021) recently found that even though increasing inclusion for children with disabilities has been an ongoing effort by some congregations, there is still a disconnect between the perceptions of the families of children with disabilities and the leadership within the faith-based settings on how supported the families feel. The study by Ault and colleagues (2021) highlights the needs for additional supports to help bridge this gap between families with children with disabilities and faith-based settings to better support the social inclusion of those with disabilities.

7.2.1 OPC Can Equip Volunteers to Better Support Children with Disabilities

One of the threads throughout this dissertation was that families wanted faith-based leaders to be trained in how to support individuals with disabilities (study 1) and church volunteers wanted to feel more equipped to serve individuals with disabilities in their faith settings (study 3). Occupational performance coaching is an approach used in occupational therapy practice that has proven to be effective at supporting the participation of children with disabilities as well as increasing the self-efficacy of adults supporting children with disabilities (Miller-Kuhaneck & Watling, 2018; Schwellnus et al., 2015; Ward et al., 2020; Ziegler & Hadders-Algra, 2020). By using the principles of occupational therapy and OPC, the gap between the needs of children with disabilities and the supports that the faith volunteers could provide was bridged. Adult volunteers were supported through evidence-based coaching from an occupational therapist and thus the children with disabilities were better able to be socially included in this setting.

7.2.2 OPC Impacts May Extend Beyond Its Participants

It was found that the use of an OPC intervention opened the door for even more supports to be provided to the children with disabilities and the families by the faith-based setting. Many supports discussed in study 1 (Chapter 2) occurred either as a direct or indirect result of the OPC intervention in study 4. In addition to the adult volunteers feeling more equipped to support the children with disabilities in their classroom, a respite night ministry was started, more trainings beyond the coached volunteers were provided, the lead pastor of the congregation started discussing disability theology and the church as a whole appeared to demonstrate more awareness of and openness to those with disabilities (as demonstrated by the volunteers that had to be turned away when helping with the respite night). These changes in the church's activities and offerings can be indicative of an attitudinal shift and an increased desire to support those with disabilities within the congregation.

These findings are important as researchers are currently trying to identify ways to change negative attitudes towards those with disabilities that continue to permeate society. Disability awareness programs have been gaining traction in research as one way to shift attitudinal barriers but are just now being researched and to date are only showing moderate short term attitudinal changes (Hayward et al., 2021). The impact of an OPC intervention in community settings and the impact on attitudes and beliefs towards those with disabilities in the community setting should be further researched to see if this is one avenue for facilitating changes in attitudes towards those with disabilities.

7.2.3 A Protocol for OPC is Created

As mentioned in study 2 (Chapter 3), in the occupational therapy literature, there were no unified definitions or approaches of coaching with the goal to support children with disabilities. The OPC protocol that was detailed as part of study 4 can be useful for occupational therapists looking to implement an OPC intervention in their practice. No written OPC protocols could be found in the literature prior to the time of this dissertation, but by using the results from the scoping review, a protocol was created and followed. In study 4 it was found that the OPC protocol written by this researcher was effective at gaining positive outcomes in supporting the social inclusion of children with disabilities. Occupational therapists can utilize this protocol when looking to implement an OPC intervention to support children with disabilities. The refinement of this protocol and detailed ways to measure the effectiveness of the intervention can provide a more standardized approach with conducting and evaluating the effectiveness of OPC in more robust studies.

7.2.4 Societal Inclusion Beyond Faith-Based Settings

While this dissertation is focused specifically on faith-based inclusion for children with disabilities, an increase in social inclusion throughout all of society is really the broader goal of this research. This dissertation introduces one transformative approach to better understanding the problem of social inclusion in a specific community setting and utilizing evidence-based practices in occupational therapy to help overcome some of the barriers. Finding effective interventions targeting the contextual level and changing attitudes and postures towards those with disabilities will be important to advance the occupational justice of those with disabilities in society.

The idea of using an OPC intervention with community volunteers is novel but could have far reaching implications for helping the societal inclusion of children with disabilities and subsequently their families. In identifying other community areas where there is or has the possibility of repeated engagement by children with disabilities and using an OPC intervention, the landscape of social inclusion throughout society can be radically changed. Children with disabilities may no longer be turned away from or placed in secluded summer camps, library programming, scout troops and others because their needs are “too much,” but the volunteers that support their involvement might be coached so that they can be more socially included with their peers.

7.3 Future Research

This dissertation lends itself to several areas of future research. Firstly, the OPC intervention study design could be repeated but with trialing varying amounts of OPC coaching sessions to determine the most efficient model of using OPC in the community while still demonstrating an effect. Additionally, the OPC intervention could be trialed with other age groups in faith-based settings to determine if it is just as effective with other ages of children. Other research has demonstrated that OPC increases self-efficacy for parents when supporting their children with a disability (Graham et al., 2013; Pashazadeh Azari et al., 2019; Suja Angelin et al., 2021). An assessment could be added in the outcomes of the protocol to determine if OPC similarly increases self-efficacy for community volunteers when working with individuals with disabilities.

The combination of understanding the experiences of volunteers (Chapter 5) and then providing intervention at the volunteer level with OPC (Chapter 6) can also be applied to other community settings to support the social inclusion of individuals with disabilities. For example, many children participate in overnight camp programming. Often, children with disabilities are relegated to their own “disability-specific” camps instead of attending more inclusive camps with their peers. By using the model to understand the experiences of the community volunteers and then providing a coaching intervention, children with disabilities may be able to attend and be socially included in camps or other similar types of activities. Other examples include training the community volunteers who provide services for activities such as boy scouts/girl scout troops, library programming, other programming which may provide activities to children in the community, or any area where there may be repeated and ongoing engagement by children with disabilities. Utilizing the study designs and approach of this dissertation researchers can investigate the effectiveness of this model in other sectors of the community. Additionally future research can examine the effectiveness of this approach when supporting the social inclusion of adults with disabilities in differing settings as well. It is also recommended that future research include qualitative measures to determine the validity of measuring social inclusion through measures of participation and social interaction by understanding the individual with disability's experience.

7.4 Conclusions

While there is still much to be done in terms of societal inclusion for individuals with disabilities, gains in social inclusion are being made for those with disabilities. The benefits to societal inclusion for children with disabilities and their families is numerous (Overmars-Marx et al., 2014; Verdonschot, et al., 2009). Further, it has been found that supporting social inclusion for those with disabilities not only elevates those with disabilities but all of society can benefit (Illinois Department of Human Services, 2011; Long, 2015). This dissertation highlights one area of societal inclusion and provides a roadmap for ways occupational therapy practitioners can support the social inclusion of children with disabilities.

APPENDICES

APPENDIX A: Outline of Occupational Performance Coaching Sessions

For all coaching sessions, all adult participants (church volunteers) were in attendance. Children did not participate in the coaching sessions.

Occupational Performance Coaching Session Outline – Session 1

- Re-Introduction to the intervention/answered questions adult participants had (participants had already completed the informed consent process)
- Administration of the Canadian Occupational Performance Measure (COPM)
- Gathered information from the volunteers regarding strategies they have already implemented
- Started discussing targeted areas of focus for the coaching session based on COPM results.

Occupational Performance Coaching Session Outline – Session 2

- Checked performance/joint reflection on how the previous Sunday morning went
- Reviewed Goal Attainment Scale targeted goal areas and discussed with the volunteers how to set up and scale the goals
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - <u>Topics discussed this week:</u> strategies for how to change the order of activities so that children were seated at the end with an activity to complete rather than doing free play. Also introduced the idea of how different activities can have different sensory impacts (hyping children up or calming them down)
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 3

- Checked performance/joint reflection on how the previous Sunday morning went
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - <u>Topics discussed this week:</u> OT shared information about the idea of self-regulation, how all children (with or without a medical diagnoses) may have difficulty with self-regulation. Started introducing the Zones of Regulation.
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 4

- Checked performance/joint reflection on how the previous Sunday morning went
- Reviewed Goal Attainment Scale goals and discussed progress towards goals for children with disabilities

- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - <u>Topics discussed this week:</u> Discussed more in depth about the Zones of Regulation- how to recognize when a child is moving into a zone that doesn’t match the level of activities, how to structure and change activities to help children stay regulated. Also discussed the Rage Cycle this week and talked through safety strategies if they were ever needed.
- Planned actions together to start implementing

Occupational Performance Coaching Session Outline – Session 5

- Checked performance/joint reflection on how the previous Sunday morning went
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - <u>Topics discussed this week:</u> Volunteers wanted a little more information on specific diagnoses common signs/symptoms of different disabilities were discussed. Additionally, the OT started to introduce the “Functions of Behavior” framework to help the volunteers understand possible causes of undesired behaviors.
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 6

- Checked performance/joint reflection on how the previous Sunday morning went
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - <u>Topics discussed this week:</u> Volunteers and OT discussed in-class activity ideas (both new activities and activities the volunteers have used in the past) and how they could impact both self-regulation levels as well as encourage more socialization among all of the children in the room.
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 7

- Checked performance/joint reflection on how the previous Sunday morning went
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - <u>Topics discussed this week:</u> One of the volunteers asked about using a visual schedule (a technique mentioned during the functions of behavior discussion). Using a visual schedule was discussed more (how to use one, and the benefits of using one) and a list of activities was created so the OT could create a visual schedule for the volunteers to trial next week.
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 8

- Checked performance/joint reflection on how the previous Sunday morning went
- Discussed progress towards GAS goals
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities

    - Topics discussed this week: Discussed how the volunteers felt the visual schedule went and discussed tweaks to be made to the visual schedule to make it more functional (bigger pictures, using magnets instead of Velcro). Also discussed further ideas for activities and games to promote more socialization.
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 9

- Checked performance/joint reflection on how the previous Sunday morning went
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - Topics discussed this week: Discussed how one parent of a child with a disability asked about a doing a disability awareness Sunday. The volunteers and OT discussed different strategies for how to facilitate this the best way. The volunteers were asked by the children's pastor to explain how to use the visual schedule in an upcoming training meeting so the volunteers and OT talked through how to explain this to others.
- Planned actions together to implement the following week

Occupational Performance Coaching Session Outline – Session 10

- Checked performance/joint reflection on how the previous week went
- Discuss progress towards GAS goals
- Re-administered the COPM
- Explored options together to overcoming identified barriers to participation and inclusion for the children with disabilities
    - Topics discussed this week: Returned to discussing Functions of Behavior and the Zones of Regulation based on some rowdy behavior by some of the other children in the room that week and strategies to help curb undesired behaviors. Discussed next steps of the study.
- Explored options together to wrap up/conclude study and talk through next steps

Occupational Performance Coaching Session Outline – Session 11 (3 weeks post intervention as the follow-up)

- Checked performance/reflect on how the previous weeks went
- Discussed progress towards GAS goals
- Re-administered the COPM
- As appropriate, provided suggestions and resources for strategies to maintain progress
- Concluded the study

APPENDIX B: Study Timeline

Week	**Date**	**Activity**	**Where**
1	Sunday 8/15	Initial Observation and SNA Survey	In Classroom
	Monday 8/16	Coaching Session 1 – Canadian Occupational Performance Measure (COPM), Goal Attainment Scaling (GAS)	Online
2	Sunday 8/22	Observations during class	In Classroom
	Wednesday 8/25	Coaching Session 2	Online
3	Sunday 8/29	Observations and SNA Survey	In Classroom
	Wednesday 9/1	Coaching Session 3	Online
4	Sunday 9/5	Observations during class	In Classroom
	Wednesday 9/8	Coaching Session 4 – Administered GAS	Online
5	Sunday 9/12	Observations and SNA Survey	In Classroom
	Wednesday 9/15	Coaching Session 5	Online
6	Sunday 9/19	Observations during class	In Classroom
	Wednesday 9/22	Coaching Session 6	Online
7	Sunday 9/26	Observations and SNA Survey	In Classroom
	Wednesday 9/29	Coaching Session 7	Online
8	Sunday 10/3	Observations during class	In Classroom
	Wednesday 10/6	Coaching Session 8 – Re-administered GAS	Online
9	Sunday 10/10	Observations during class	In Classroom
	Wednesday 10/13	Coaching Session 9	Online
11	Sunday 10/24	Observations and SNA Survey (pushed out by 1 week due to only two child participants available the previous week)	In Classroom
	Wednesday 10/27	Coaching Session 10 – Re-administered the COPM and GAS	Online
14	Sunday 11/14	Observations and SNA Survey – Re-administered the COPM and GAS **Study Concludes**	In Classroom

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Additional Trainings

Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

- University of Cincinnati University Center on Excellence in Developmental Disability (UC-UCEDD). Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio. April 2017.

American Occupational Therapy Association Fellowship

- Pediatric Fellow. Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio. June 2016-June 2017.

Professional Positions

University of Cincinnati, Department of Rehabilitation, Exercise and Nutritional Sciences, Cincinnati, Ohio. *Instructor.* September 2018-Present

Gateway Rehabilitation Hospital. Florence, Kentucky. *Case Manager, PRN*. February 2021-Present.

University of Cincinnati, Department of Rehabilitation, Exercise and Nutritional Sciences, Cincinnati, Ohio. *Research Assistant*. April 2018-September 2018

Cincinnati Children's Hospital Medical Center. Cincinnati, Ohio. *Occupational Therapist I*. June 2017-March 2018

Cincinnati Children's Hospital Medical Center. Cincinnati, Ohio. *Occupational Therapy Fellow*. June 2016-June 2017

Independent Contractor for Fort Thomas Independence Schools. Fort Thomas, Kentucky. *School-Based Occupational Therapist*. September 2013-May 2016.

Independent Contractor for Southgate Independent Schools. Southgate, Kentucky. *School-Based Occupational Therapist*. August 2015-May 2016.

Pediatric Therapy Associates. Fort Thomas, Kentucky. *Early Intervention Occupational Therapist.* September 2014-May 2016.

Independent Contractor for Ludlow Independent Schools. Ludlow, Kentucky. *School-Based Occupational Therapist.* September 2013-May 2015.

Gateway Rehabilitation Hospital. Florence, Kentucky. *Occupational Therapist, PRN*. September 2013-September 2015.

Professional Publications

Ault, M.J., Slocum, V., Collins, B.C., Leahy, M.M. and **Miller, V**. (2021). Perceptions of faith leaders on the inclusion and participation of individuals with disabilities in their communities. *Journal of Disability and Religion.* Doi: 10.1080/23312521.2021.1932691

Miller, V.P., & Skubik-Peplaski, C. (2020). A systematic review of supports for participation in faith settings for individuals with disabilities. *American Association on Intellectual and Developmental Disabilities: Inclusion, 8*(2), 105-23.

Will, M.N., Currans,, K., Smith, J., Weber, S., Duncan, A., Burton, J., Kroeger-Geoppinger, K., **Miller, V**., Stone, M., Mays, L., Luebrescht, A., Heeman, A., Erickson, C., & Anixt, A. (2018). Evidence-based interventions for children with autism spectrum disorder. *Current Problems in Pediatric and Adolescent Health Care*, 1-17.

Harpster, K., & **Miller, V.** (2017). Clinical bottom line: Commentary on "Intensive unimanual versus bimanual training in upper extremity function in children with CP: Systematic review". *Pediatric Physical Therapy.* 10/2017

Professional Presentations

Complementary Perspectives: An Inter-Disciplinary Approach to Independent Living Skills (Presentation). **Miller V**., Wolfer, K., & Goings, J. State of the Art Annual Conference. Virtual. November 2021.

Does Every Child Have a Church? (Presentation). **Miller, V**. Special Opportunities Abilities and Relationships (SOAR) Annual Conference. Virtual. October 2021.

Understanding the Experiences of Faith-Based Volunteers Serving Children with Intellectual and Developmental Disabilities (IDD) in Their Faith Settings (Presentation). **Miller, V.** University of Kentucky College of Health Sciences 20th Anniversary Celebration. Virtual. May 2021.

Understanding the Experiences of Faith-Based Volunteers Serving Children with Intellectual and Developmental Disabilities (IDD) in Their Faith Settings. (Poster). **Miller V,** Thompson, B., Schwarz, A., & Cartwright, B. University of Cincinnati College of Allied Health Sciences. Annual PRaISE Conference. Virtual. April 2021.

A Model for Interdisciplinary Synergy in Comprehensive Transition Programs. (Presentation – Cancelled due to COVID). **Miller, V**., Wolfer, K, & Goings, J. State of the Art Annual Conference on Inclusive Postsecondary Education and Individuals with Intellectual Disability. Syracuse, NY. October 2020.

A Systematic Review of Supports for Participation in Faith Settings for Individuals with Disabilities (Poster). **Miller, V.** & Skubik-Peplaski, C. University of Kentucky College of Health Sciences Annual Conference. Lexington, KY May 2019.

Feasibility of a Community-Based Occupational Therapist-Led Life Management Intervention for Individuals with Stroke (Poster). Hill, V., Towfighi, A., & **Miller, V**. American Occupational Therapy Association Annual Conference. New Orleans, LA, April 2019.

Does Every Child Have a Church? (Presentation). **Miller, V.** Stadia's Bloom Annual Conference. Lakeside, OH, September 2018.

Families of Individuals with Developmental Disabilities Perceived Supports and Barriers to Visiting the Cincinnati Zoo and Botanical Garden (Poster). **Miller, V**., Richard, J., Wolken, M., Farmer, T., & Smith, J. American Occupational Therapy Association Annual Conference. Salt Lake City, UT, April 2018.

Families of Individuals with Developmental Disabilities Perceived Supports and Barriers to Visiting the Cincinnati Zoo and Botanical Garden (Presentation). **Miller, V.** Maternal and Child Health Bureau's Making Lifelong Connections Conference. Tampa, FL, April 2018.

How to Utilize a Sensory Room. (Presentation). **Miller, V**. Got Autism. Cincinnati, OH September, 2015.

Performance Appraisal of School-based Occupational and Physical Therapists (Presentation). O'Brien, S., **Miller, V**. 6th Annual PREPaRE Conference, Lexington, Kentucky. March 2015.

Performance Evaluation in Schools: Updates Shaping Practice (Presentation). O'Brien, S., **Miller, V**., Kentucky Occupational Therapy Association Annual Conference. Lexington, KY. September 2014.

The Sensory Profile and Activity Choice of a Child with Autism Spectrum Disorder: A Case Study (Poster). **Miller, V**., & O'Brien, S. OCALICON Annual Conference. Columbus, OH, 2012.